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International Pain Summit Steering Committee

Michael Cousins, AM MD DSc FRCA FANZCA FFPMANZCA FACHPM (RACP), Australia, Chair

Harald Breivik, MD, DMsc, FRCA, Norway
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Diederik Lohman, USA
Mary Lynch, MD, Canada
Henry Lu, MD, Philippines
Germán Ochoa, MD, Colombia
Catherine Price, MD, United Kingdom
M. R. Rajagopal, MD, India
Olaitan Soyannwo, MD, Nigeria
Welcome
IASP President – Eija Kalso, MD, PhD

Setting the Stage
Objectives for the Day
Steering Committee Chair – Michael Cousins, MD, DSc

Video – The Problem of Pain
Living with Pain

Establishing a Human Right to Pain Management
Margaret Somerville, LLD, McGill University

Patient Perspectives
A Patient with Chronic Pain
Andrea Crowe

Wife of a Cancer Patient
Leslie Hickman

The Emerging Roles of People with Pain in Pain Care
Lynn Cooper, Canadian Pain Coalition

Country Initiatives
Canada
Honourable Marlene Jennings, Deputy House Leader for the Official Opposition and Liberal Critic for Government Ethics and Democratic Reform

Malaysian Deputy Director General of Health, Ministry of Health
Datuk Dr. Nor Hisham Abdullah

Pain Medicine in the United States
Albert Osbahr, MD, American Medical Association

The First National Pain Strategy, Portugal
Jose Romao, Dr. Med, President, Associação Portuguesa para o Estudo da Dor

The Chief Medical Officer’s Report: One Year On
Benjamin Ellis, MD, Senior Policy Adviser, Arthritis Research Campaign, United Kingdom

Bogotá - a City with No Pain Project
Germán Ochoa, MD, University Hospital, Bogotá

Paths to Progress in Pain Management: Patient-Provider Coalitions and the Medical Home
Rollin M. Gallagher, MD, MPH, Board of Directors, American Pain Foundation
Global Policy Making

IASP Medications Task Force Survey Response
Beverly Collett, MB BS, IASP Executive Committee

Global Pain Initiatives
James Cleary, MB BS, University of Wisconsin, USA

Human Rights Organizations: Pain Relief as a Human Right
Diederik Lohman, Human Rights Watch, USA

Human Rights and “The Declaration of Montreal”
Michael Cousins, MD, DSc

10:15 Break

The Problem of Pain
Mary Lynch, MD, Canadian Pain Society

Desirable Characteristics of National Pain Strategies
Cathy Price, MD, UK

Special Issues and Strategies in Developing Countries
M.R. Rajagopal, MD, India

Special Issues of Pain in Children
G. Allen Finley, MD, Canada

Panel Discussion of Presentations and Questions
CHAIR: Mary Lynch, MD
PANEL: Cathy Price, MD, Lynn Cooper, M.R. Rajagopal, MD,
Mary Cardosa, MD, Philipp Lippe, MD, Germán Ochoa, MD, Harald Breivik, MD

12:20 Lunch (provided): 30 minutes

Objectives of Workshops/Round Table Discussions
Michael Cousins, MD DSc

Round Table Discussions on Two Documents

Group Reports - #1 “Desirable Characteristics”

Group Reports - #2 “Declaration of Montréal”

Summary of Revisions

Discussion and Vote on Acceptance of Two Documents
(subject to accepted modifications)

4:00 CLOSE

Refreshments available during afternoon session
IASP Documents
Desirable Characteristics of National Pain Strategies:
Recommendations by the International Association for the Study of Pain

In the past four decades there have been significant advances in our understanding of the complexity of the nervous system and in our knowledge about the causes of pain. Research has established that there are essentially two types of pain (acute and chronic). There is both cancer-related and noncancer pain. Effective treatments exist; nevertheless, the best available evidence indicates a major gap between an increasingly sophisticated understanding of the pathophysiology of pain and the widespread inadequacy of its treatment.

In many nations, this gap is unnoticed and unmeasured. Many public health agencies seem unaware of the scale of the problem of unresolved pain, with the result that the population’s needs remain unaddressed, even though low-cost solutions may be available.

This gap has prompted a series of declarations and actions by national and international bodies advocating better pain control (see the Summary Chart for examples). These calls to action are based on three propositions:

- Pain, no matter which type, is inadequately treated for a variety of cultural, attitudinal, educational, political, religious, economic, and logistical reasons.
- Inadequately treated pain has major physiological, psychological, economic, and social ramifications for patients, families, and society.
- It is within the capacity of all developed and many developing countries to significantly improve the treatment of pain without incurring substantial costs, through addressing some of the barriers that exist.

The impact of inadequately treated pain appears remarkably similar, no matter where in the world it is measured [3,6,7,15,18,21,22,25].

- One in five people has moderate to severe chronic pain.
- One-third of these people have experienced lost ability to perform wage-earning or other work.

Imaging studies have shown that persistent pain is associated with significant functional, structural, and chemical changes in the brain, thus putting such pain into the realm of a disease state [24]. Patients who have chronic pain disorders with known causes (e.g., osteoarthritis or cancer) or unknown causes (e.g., nonspecific low back pain) have altered cerebral pain processing and loss of gray matter, leading to impaired function [1,20,26]. Increasing evidence shows that chronic pain is in fact a separate disease entity with associated patterns of central nervous system abnormalities. Yet the considerable breakthroughs in scientific knowledge about the phenomenology, pathophysiological mechanisms, and related treatment advances for pain diseases and disorders are barely acknowledged in medical training, with the result that people with severe, poorly relieved pain are often stigmatized and disbelieved. The Declaration of Montreal highlights the need for people in pain to assert their rights to care.
Advances in medical knowledge have led to improved understanding of how to better manage pain, in terms of both primary and secondary prevention of chronic disability and improved multidisciplinary management of those most severely affected by chronic pain. However, studies [7,19] show that:

- Fewer than 50% of patients with cancer pain receive effective relief
- Fewer than 50% of patients with acute pain receive effective relief
- Fewer than 10% of patients with chronic noncancer pain gain access to effective management

Many institutions such as the National Institutes for Health (NIH) in the United States and the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom have published guidance on cost-effective interventions for the management of pain. Summarizing the literature [4,11,14,28], we now know that:

- 90% of acute pain can be successfully treated at low cost
- 75% of cancer pain can be successfully treated at low cost
- 80% of patients with chronic noncancer pain can now be effectively managed

Worldwide, if we continue to fail at effective pain management, we will continue to pay a staggering and unnecessary price [8].

The International Association for the Study of Pain (IASP) supports the view that every country should have a pain strategy that specifies the extent of the problem and what should be done about it. This document sets out recommendations for the essential elements of any national pain strategy and for the process of achieving a strategy. It accompanies the Declaration of Montreal, which asserts the human rights of those in pain. It is hoped that this document will act as an impetus to clinicians, educators, administrators, and governmental or professional organizations involved in the establishment and maintenance of standards for pain services to take action to prevent the continued waste of millions of lives and resources.

National Strategy Development

IASP members submitted health policies on pain in 19 countries to a review by a working party. Seven countries were found to have a comprehensive strategy to address the management of pain, and the remainder had strategies focusing mainly on opioid control. These strategies are contained within the Summary Chart.

Combined experience has demonstrated that several steps are helpful in developing a national strategy. The following points represent a distillation of these steps.

1. Understanding the scale of the problem posed by poorly managed pain

Excellent large-scale surveys in many countries have established that chronic noncancer pain ranks as the third most costly health care problem after cancer and cardiovascular disease and that the problem is costlier in developing countries [15,25]. Poorly relieved pain also leads to accelerated mortality [23].
In spite of this information, the extent of the problem is poorly understood because pain and its effects are being hidden in other forms of measurement. As it is often initially associated with other disease processes, pain is often inadequately recorded, both in clinical records and in the administrative coding that is often used as a source for epidemiological studies. For example, the World Health Organization’s “Global Health Risks,” which aims to identify forthcoming major health risks to the world, mentions only the impact of low back pain on work [31]. Without generating new data, governments may fail to appreciate the size of the problem. Countries should carry out a basic health survey to understand this problem by asking questions specifically about pain, its management, and its impact. This information serves as a useful baseline from which to measure the impact of any interventions a government may introduce [12].

2. Understanding the barriers to effective pain management

There may be professional, public, or system barriers. Common professional barriers include a lack of knowledge and skills, as well as inappropriate attitudes and behaviors that demonstrate a lack of understanding of the problem. System barriers may include a lack of resources, outmoded financial incentives, or poor coordination of care. Population health knowledge and awareness may be poor. Taboos may exist toward both those who seek treatment for their pain and some of the treatments that may benefit them. There may be problems with drug availability, training of health care workers, or gaps in policy development. A lack of resources to ensure coordination of pain management between both primary and secondary care and health care services and social services may exist [19].

Specific examples of barriers include:

- Educational gaps: national surveys in Canada and the United Kingdom have identified that veterinarians receive more training in pain management than do health care professionals who care for people [9,30].
- Best-practice pain management often requires coordinated interdisciplinary assessment and management, yet current reimbursement and insurance arrangements mean that treatments with limited evidence of efficacy, including some surgeries and invasive medical treatments that carry the risk of complications or dependency, are often favored over a combination of less invasive and less costly approaches that promote independence.
- Excessive waiting times for treatment in chronic pain can lead to a deterioration in health [16,29], risking aggravation of the pain condition and further decreases in quality of life, eventually requiring more expensive interventions.
- Pain research is grossly underfunded, considering the burden of illness [5,17].
- There is a lack of public health focus on pain as a priority [10].

3. Developing a clear plan to deliver change

Desirable characteristics of any plan, as recommended by the International Association for the Study of Pain, have been classified into four broad areas:

- Pain research
• Pain education
• Patient access and care coordination
• Monitoring and quality improvement

It is essential to
• Identify those who have the capacity to deliver change
• Establish a timeline for achieving change
• Measure the impact of change on a health system and on the society in which it operates

### Desirable Characteristics of National Pain Strategies

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<tr>
<th>Characteristics</th>
<th>Examples</th>
<th>Responsible Parties</th>
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<td><strong>Pain Research</strong></td>
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<tr>
<td>▪ Epidemiological</td>
<td>A national health survey.</td>
<td>Public health services, health economists</td>
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<tr>
<td>▪ Translational/bASIC science</td>
<td>Prioritization of pain for funding opportunities that target gaps in pain treatment, knowledge transfer, education, and policy.</td>
<td>Federal health research funding bodies</td>
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<td><strong>Pain Education</strong></td>
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<td>▪ Undergraduate/medical school</td>
<td>At an early stage in training to equip trainees with both the knowledge and skills to address all types of pain. The IASP Core Curriculum sets out standards for education in pain.</td>
<td>Centers of learning, regulatory bodies</td>
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<tr>
<td>▪ GME-primary care</td>
<td>All primary care practitioners to have the knowledge and skills to perform a basic pain assessment and develop a management plan.</td>
<td>Commissioners of health care</td>
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<tr>
<td>▪ GME-specialists</td>
<td>There should be physicians trained to a specialist level in pain medicine.</td>
<td>Centers of learning, regulatory bodies</td>
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<tr>
<td>▪ CME-physicians</td>
<td>All physicians should have ongoing education in pain.</td>
<td>Commissioners of health care</td>
</tr>
<tr>
<td>▪ Allied health</td>
<td>Allied health professionals should all have parts of their core curricula dedicated to pain management</td>
<td>Centers of learning, regulatory bodies</td>
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<tr>
<td>▪ Public awareness</td>
<td>The population needs education to understand that people may be in pain and thus struggle to maintain their lives without wanting to communicate their vulnerabilities for fear of discrimination.</td>
<td>Providers of health care, patient organizations, and health educator programs</td>
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<td><strong>Patient Access and Care Coordination</strong></td>
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<td>▪ To care</td>
<td>Rapid access to pain care to prevent deterioration to poor function. Hospitals should have at least one doctor and one nurse with training in pain assessment and management.</td>
<td>Health care policy makers, providers and commissioners of health care</td>
</tr>
<tr>
<td>▪ To medicines</td>
<td>The WHO list of essential medicines should be available. Ensure access to oral morphine for cancer pain by identifying barriers to its access and by taking steps to overcome them.</td>
<td>Government regulatory agencies, drug enforcement agencies, and key clinical staff</td>
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<td>Characteristics</td>
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<td>To information</td>
<td>Accurate signposting to the right help as early as possible with a fully informed choice of options. Any pain management program must engage the community both in advocacy and in use of trained volunteers in the care program.</td>
<td>Providers and commissioners of health care</td>
</tr>
<tr>
<td>Specialist referral</td>
<td>Pain networks can ensure excellent relationships between providers. Where secondary care exists, there should be a vertical system for escalation of referrals of difficult problems from primary, through secondary, to tertiary care centers. All tertiary care centers should have specialized pain clinics with facilities for expert psychosocial support and interventional procedures.</td>
<td>Commissioners of health care</td>
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<tr>
<td>Interdisciplinary approach</td>
<td>A biopsychosocial approach to assessment and management.</td>
<td>Providers of health care</td>
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<tr>
<td>Self-care</td>
<td>Care should be in partnership with family and/or caregivers. Adoption of approaches that support self-care.</td>
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</table>

**Monitoring/Quality Improvement**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Examples</th>
<th>Responsible Parties</th>
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<tbody>
<tr>
<td>Time to care</td>
<td>Setting standards for access times and work plans that allow sufficient time.</td>
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<tr>
<td>Quality of service</td>
<td>Patient experience should be routinely sought; there should be a reduction in waiting times for treatments.</td>
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<tr>
<td>Quality of life</td>
<td>Improvements in the individual patient’s quality of life, according to both generic and disease-specific measures.</td>
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<tr>
<td>Economic burden</td>
<td>Monitoring should include work absence due to pain, prescription costs, urgent care, and use of other services.</td>
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<tr>
<td>Special needs</td>
<td>Special populations include the very young and very old, victims of torture, those with learning difficulties, ethnic minorities, and impaired persons.</td>
<td>Providers and commissioners of health care</td>
</tr>
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</table>

**References**


DECLARATION OF MONTRÉAL

Declaration that Access to Pain Management Is a Fundamental Human Right

We, as delegates to the International Pain Summit (IPS) of the International Association for the Study of Pain (IASP) (comprising IASP representatives from Chapters in 84 countries plus members in 126 countries, as well as members of the community), have given in-depth attention to the unrelieved pain in the world,

Finding that pain management is inadequate in most of the world because:

- The World Health Organization (WHO) estimates that 5 billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain.
- There are major deficits in knowledge of health care professionals regarding the mechanisms and management of pain.
- There are severe restrictions on the availability of opioid medication, which is critical to the management of pain.
- Most countries have no national policy at all or very inadequate policies regarding the management of pain as a health problem, including an inadequate level of research and education.

And, recognizing the intrinsic dignity of all persons and that suffering is harmful and should be avoided, we declare that:

The following human rights must be recognized throughout the world.

Article 1. The right of all people to have access to pain management without discrimination, in particular, on the basis of age, sex, gender, medical diagnosis, race, religion, culture, marital status, or political or other opinion (Footnotes 1-3).

Article 2. The right of people in pain to be informed about how their pain can be assessed and the possibilities for treatment (Footnote 4). Recording the results of assessment, e.g. as the ‘5th vital sign’, can focus attention on unrelieved pain, triggering appropriate treatment interventions and adjustments.

Article 3. The right to access an appropriate range of effective pain management strategies (Footnote 5), supported by policies and procedures that must be appropriate for the particular setting of health care and the health professionals employing them.
**Article 4.** The right of people with pain to have access to all appropriate medicines, including but not limited to opioids, and to have access to health professionals skilled in the use of such medicines (Footnote 6). In resource-poor countries it is important to at least ensure access to oral immediate-release morphine.

**Article 5.** The right of people with pain to assessment and treatment by an appropriately educated and trained interdisciplinary team at all levels of care. (In resource-poor countries the team should include, at a minimum, a doctor and a nurse with training in pain management).

**Article 6.** The right of people with pain to treatment under a health policy framework that is compassionate, empathetic, and well-informed. This includes legal systems (including laws relating to opioids), the conditions of employment that employers impose on employees, compensation systems, insurance bodies, and government agencies.

**Article 7.** The right of people with pain to have access to best practice nonmedication methods of pain management (ranging from relaxation and physiotherapy methods to more complex cognitive behavioral treatment) and to specialist-performed interventional methods, depending upon the resources of the country.

**Article 8.** The right of people with chronic pain to be recognized as having a disease entity, requiring access to management akin to other chronic diseases.

**Article 9.** The obligation of all health care professionals in a treatment relationship with a patient, within the scope of the legal limits of their professional practice and taking into account the treatment resources reasonably available, to offer to a patient in pain the management that would be offered by a reasonably careful and competent health care professional in that field of practice. Failure to offer such management is a breach of the patient’s human rights.

**Article 10.** The obligations of governments and all health care institutions, especially hospitals, within the scope of the legal limits of their authority and taking into account the health care resources reasonably available, to establish laws, policies, and systems that will help to promote, and will certainly not inhibit, the access of people in pain to fully adequate pain management. Failure to establish such laws, policies, and systems is unethical and a breach of the human rights of people harmed as a result.

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*Note:* This Declaration has been prepared having due regard to current general circumstances and modes of health care delivery in the developed and developing world. Nevertheless, it is the responsibility of: governments, of those involved at every level of health care administration, and health professionals to update the modes of implementation of the Articles of this Declaration as new frameworks for pain management are developed.
Footnotes

1. International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966). The State parties of the ICESCR recognize “the right of everyone to the highest attainable standard of physical and mental health” (Art. 12), creating the “conditions which would assure to all medical service and medical attention in the event of sickness.”

2. Universal Declaration of Human Rights (1948): Rights to Health (Article 25); Convention on the Rights of a Child (Article 24); Convention on the Elimination of All Forms of Discrimination Against Women (Article 12); Convention on the Elimination of All Forms of Racial Discrimination (Article 5(e)(iv)).

3. The Committee on Economic, Social and Cultural Rights. General Comment No.14, 22nd Session, April-May 2000 E/C 12/2000/4. “Core obligations” of all signatory nations included an obligation to ensure access to health facilities, goods, and services without discrimination, to provide essential drugs as defined by WHO, and to adopt and implement a national health strategy.


5. The UN Universal Declaration of Human Rights (1948) (Article 5) states: “No one shall be subjected to torture or to cruel, inhuman or degrading treatment…”

Comment: Deliberately ignoring a patient’s need for pain management or failing to call for specialized help if unable to achieve pain relief may represent a violation of Article 5.

6. The UN Special Rapporteur on the Right to Health and the UN Special Rapporteur on the question of torture and other cruel, inhuman, and degrading treatment stated: “The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.”

References


Summary Chart - Examples of National Pain Care Strategies, Relevant Statements and Proposals, and Enacted Government Regulations/Laws

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- = Recommended by non-governmental organizations
- = Proposed by national governmental organizations
- = Enacted into national law, national regulations, or national statute

Prepared for IASP by: John P. Ney, MD
Survey Results:
IASP National Pain Management Assessment Survey

Purpose
To obtain information on an international scale regarding the state of pain medicine at the primary care and specialist level, and on obstacles to improvement in pain management through policy initiatives and government interventions.

Methods
A link to an online questionnaire was sent to 84 International Association for the Study of Pain (IASP) chapter presidents, each representing the pain medicine faculty for a particular country. The questionnaire consisted of 29 largely multiple-choice questions in three areas: (1) Pain treatment by primary care providers, (2) pain treatment by specialists, and (3) the role of the government in regulation and oversight of pain management. Several open-ended questions were also asked. The respondents were encouraged to answer all questions to the best of their knowledge, although they were allowed to skip individual questions.

Results
As of 12 August, 29 of 85 responses (response rate of 34%) representing 28 different countries were collected. The majority of respondents were from developing nations, although nations with developed health care systems, such as Canada, Australia, and the UK were also represented. The response rate per multiple-choice question ranged from 62% to 76%. The response rates below were based on respondents who actually answered the relevant question in the survey.

1) Primary care: With regard to primary care, the majority of respondents noted that their nation’s populace had access to primary care providers (PCPs) (67.3% of question respondents). Most PCPs were medical doctors (65% of respondents), although nurses also played a significant role (>25% of primary care in respective nations) for a quarter of respondents. 44% of respondents indicated that less than half of PCPs in their nation did not have residency training, and 48% of respondents noted that less than 5% of PCPs had supervised clinical rotations in a pain-related medical specialty. Indeed, lack of supervised clinical training in pain for primary care was cited as one of the top three national challenges in pain management by 42% of respondents. However, pain diagnosis and management was felt to be a significant portion (>1/4 of practice) for 45% of respondents. Sixty percent of respondents noted some barrier to PCP prescription of opiates, 45% noted some restriction on the prescription of expensive adjunctive pain medications (anticonvulsants and antidepressants) by PCPs, and 70% indicated some limitation on PCPs performing pain-related procedures, such as joint injections. Greater than 70% of respondents indicated that PCPs in their nation were able to refer to an allied health provider (physical therapist, counselor, nurse, or pharmacist) to help manage pain disorders.
2) **Pain specialist care:** In assessing challenges to improving pain management on a national level, lack of pain specialists was cited by 100% of respondents. Ninety percent of respondents indicated that pain specialists represented 5% or less of the health care providers in their nation, with 47% of respondents indicating that 5% or less of pain specialists were MDs. Insufficient formal supervised clinical training for pain specialists was noted by 37% of those surveyed. For 69% of respondents indicated that only one-fourth or less of the total practice of pain specialists was related to the diagnosis or treatment of pain. Nearly 40% of respondents indicated that at least a quarter of pain specialist time was spent managing chronic pain with oral medications, while only 17% indicated that pain specialists in their nation spent greater than one-fourth of their practice performing procedures. A significant portion of respondents (21%) indicated that more than one-fourth of pain specialists’ practice was spent educating nonspecialists. For types of pain (cancer-related, neuropathic, postprocedure, other chronic pain), chronic non-neuropathic/noncancer pain was the most commonly seen (39% of respondents indicating >25% of pain specialist practice). Respondents indicate that patients were more likely to be referred to a pain specialist by a PCP or other medical specialist than to be self-referred.

3) **Government role in pain management:** Eighty-four percent of respondents indicated that the government was responsible for health care for all of its citizens. A government entity specifically tasked with pain management was noted by only eleven percent of respondents, while 26% indicated that their government had published referral guidelines to pain specialists, and there was no government involvement in pain specialist training and certification according to 68% of respondents. Ninety-five percent of survey respondents indicated at least moderate difficulty in contacting government legislators, administrators and political figures regarding health care and pain management. Of 18 possible challenges for national pain management strategies, lack of government prioritization of pain management was cited by 58% of respondents.

**Conclusions**

Our survey of IASP chapter presidents provides a description of some of the major problems facing pain management on a global scale. The shortage of pain specialists, insufficient training for specialists and primary care providers in pain management, and the minimal role of national governments were each noted as prominent challenges in reforming pain management in their respective nations. Although our results should not be interpreted as definitive, they point to the need for greater education of health care providers and involvement of government in pain practice.
Supporting Materials
Access to pain treatment as a human right

Diederik Lohman, Rebecca Schleifer, Joseph J Amon*

Abstract

Background: Almost five decades ago, governments around the world adopted the 1961 Single Convention on Narcotic Drugs which, in addition to addressing the control of illicit narcotics, obligated countries to work towards universal access to the narcotic drugs necessary to alleviate pain and suffering. Yet, despite the existence of inexpensive and effective pain relief medicines, tens of millions of people around the world continue to suffer from moderate to severe pain each year without treatment.

Discussion: Significant barriers to effective pain treatment include: the failure of many governments to put in place functioning drug supply systems; the failure to enact policies on pain treatment and palliative care; poor training of healthcare workers; the existence of unnecessarily restrictive drug control regulations and practices; fear among healthcare workers of legal sanctions for legitimate medical practice; and the inflated cost of pain treatment. These barriers can be understood not only as a failure to provide essential medicines and relieve suffering but also as human rights abuses.

Summary: According to international human rights law, countries have to provide pain treatment medications as part of their core obligations under the right to health; failure to take reasonable steps to ensure that people who suffer pain have access to adequate pain treatment may result in the violation of the obligation to protect against cruel, inhuman and degrading treatment.

Background

Chronic pain is a one of the most significant causes of suffering and disability worldwide, and a common symptom of both cancer and HIV/AIDS. Up to 70% of cancer patients suffer from pain [1] and, among individuals living with HIV/AIDS, wide estimates of pain prevalence at all stages of infection have been reported [2-18]. While pain prevalence is diminished among individuals on antiretroviral therapy [16], studies continue to document the under-recognition and under-treatment of pain, even among individuals being treated for HIV infection [19-22]. Pain treatment is also related to gender, as HIV-infected women with pain are twice as likely to be under-treated as their male counterparts [21].

Pain has a profound impact on the quality of life and can have physical, psychological and social consequences. It can lead to reduced mobility and a consequent loss of strength, compromise the immune system and interfere with a person’s ability to eat, concentrate, sleep, or interact with others [23]. A World Health Organization (WHO) study found that people who live with chronic pain are four times more likely to suffer from depression or anxiety [24,25]. The physical and psychological effects of chronic pain influence the course of disease [26]. Chronic pain can indirectly influence disease outcomes by reducing treatment adherence.

The WHO Pain Relief Ladder recommends the administration of different types of pain medications, depending on the severity of pain, and is the basis of modern pain management [27]. For mild pain, the WHO calls for basic pain relievers, usually widely available without prescription. For mild to moderate pain, it recommends a combination of basic pain relievers and a weak opioid, such as codeine. For moderate to severe pain, the WHO has recognized that strong opioids, such as morphine, are ‘absolutely necessary’ [28].

The WHO’s recognition of the absolute necessity of opioid analgesics has reflected the consensus among health experts for decades. Almost 50 years ago, the United Nations (UN) member states adopted the 1961 Single Convention on Narcotic Drugs, declaring the medical use of narcotic drugs indispensable for the relief of pain and mandating an adequate provision of narcotic...
drugs for medical use [29]. The International Narcotics Control Board (INCB), charged with monitoring the implementation of the UN drug conventions, clarified in 1995 that the Convention ‘establishes a dual drug control obligation: to ensure adequate availability of narcotic drugs, including opiates, for medical and scientific purposes, while at the same time preventing illicit production of, trafficking in and use of such drug’ [30]. The WHO has included both morphine and codeine in its Model List of Essential Medicines [31]. Various other international bodies, such as the UN Economic and Social Council and the World Health Assembly, have also called on countries to ensure an adequate availability of opioid analgesics [32-35].

Yet, despite this clear consensus that pain treatment medications should be available, approximately 80% of the world population has either no, or insufficient, access to treatment for moderate to severe pain [36]. Millions of people living with cancer and HIV - including 1 million end-stage HIV/AIDS patients - suffer from moderate to severe pain each year without treatment [36].

Pain treatment medications are not evenly distributed worldwide. Approximately 89% of the total world consumption of morphine occurs in North America and Europe [37]. Low and middle income countries consume only 6% of the morphine used worldwide [38], even though they are home to about half of all cancer patients [26] and more than 90% of HIV infections [39]. However, inadequate pain management is also prevalent in developed countries. In the USA, the lack of the availability of pain medication in pharmacies, misinformation about addiction on the part of both patients and providers and fear of criminal sanctions for prescribing pain medicines are significant limiting factors [40]. Studies in Western Europe also document an under-estimation of pain severity and under-treatment of pain [17].

This article outlines the common obstacles to the provision of pain treatment and palliative care and calls for the reform of laws and policies inhibiting access to pain treatment worldwide. It also examines access to pain relief medicine in relation to the obligations of states under international human rights law. Identifying state obligations in the context of the HIV/AIDS epidemic has been a powerful mechanism for mobilizing attention and compelling response. By developing a human rights framework related to access to pain relief medicines, individuals living with HIV, as well as those with cancer or other causes of pain, can more effectively unite to demand the accountability of governments to respect, protect and fulfill their rights.

**Discussion**

Barriers to access to pain treatment globally include: (1) the failure of governments to put in place functioning drug supply systems; (2) the failure to enact policies on pain treatment and palliative care; (3) poor training of healthcare workers; (4) the existence of unnecessarily restrictive drug control regulations and practices; (5) fear among healthcare workers of legal sanctions for legitimate medical practice; and (6) the unnecessarily high cost of pain treatment.

**Failure to ensure functioning and effective supply system**

Opioid analgesics are controlled medicines and, as such, their manufacture, distribution and prescription are strictly regulated. The 1961 Single Convention on Narcotic Drugs has created a system for the regulation of supply and demand, overseen internationally by INCB and nationally by special drug control agencies. Every year, countries submit estimates of their need for morphine and other controlled medications to INCB, which approves each country’s supply. Cross-border transactions must be authorized and registered by INCB.

As the production, distribution and dispensation of controlled medicines are under exclusive government control, governments must also put in place an effective system of distribution in order to provide healthcare providers and pharmacies with a continuous and adequate supply of the medications. Yet, many governments, as a result of resource limitations or lack of political will, have failed to put in place effective supply systems for controlled medicines [41]. More fundamentally, there is a lack of a common understanding of opi ate pain relief needs and accessibility. A 2006 African Palliative Care Association survey found that, while drug control agencies in Kenya, Tanzania and Ethiopia believed the regulatory system worked well, morphine consumption in each of these countries was far below the estimated need and the palliative care providers surveyed identified myriad problems with the regulatory system [42].

While UN drug conventions require countries to submit estimates of their need for controlled substances based on a careful assessment of population needs, some countries either submit no estimates or submit only symbolic estimates. For example, the West African nation of Burkina Faso estimated that it would need 49 g of morphine in 2009 [43]. Based on an estimate for a terminal cancer or end-stage AIDS patient of a daily need for 70 mg of morphine for an average of 90 days, this amount would be sufficient for about eight patients. Even in countries that estimate a need for considerably greater absolute quantities of morphine, population needs are vastly underestimated (Table 1).

Without an effective distribution system, sufficient supply does not ensure accessibility. As controlled medications may only be transferred between parties that have been authorized under national law, governments must ensure that a sufficient number of pharmacies are
licensed to handle morphine and that the procedures for procuring, stocking and dispensing it are practical.

Yet, in some cases, government regulations allow only a few institutions to stock the medication, sharply limiting accessibility [42]. In other countries, excessively burdensome procedures for procurement, dispensing and accounting effectively discourage health institutions from procuring the required morphine [44]. Where hospitals and pharmacies do stock morphine, interruptions in stock are common [42,45].

| Table 1 Morphine estimates, mortality and pain treatment need. |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Country         | Cancer deaths 2002 estimate | AIDS deaths 2005 estimate | No. of individuals expected to need pain treatment in 2009 | Estimated total morphine need in 2009 (kg) | Estimate of morphine need provided by country to INCB for 2009 (kg) | No. of individuals estimate is sufficient for | Percentage of those needing treatment who would be covered by estimate |
| Benin           | 13400           | 9986            | 15786           | 96              | 0.5            | 83              | 0.50%           |
| Senegal         | 17625           | 5432            | 16816           | 102             | 0.6            | 99              | 0.60%           |
| Rwanda          | 14196           | 21956           | 22335           | 136             | 0.8            | 132             | 0.60%           |
| Gambia          | 2395            | 1430            | 2631            | 16              | 0.18           | 31              | 1.20%           |
| Bhutan          | 727 >10 per 100,000 | 582            | 3.5             | 0.08           | 14             | 2.30%           |
| Burkina Faso    | 23262           | 13067           | 25143           | 153             | 0.05           | 8               | 0.03%           |
| Eritrea         | 6240            | 5959            | 7972            | 48              | 0.075          | 12              | 0.15%           |
| Gabon           | 2071            | 4457            | 3886            | 24              | 0.088          | 14              | 0.40%           |
| Swaziland       | 1837            | 17577           | 10258           | 62              | 0.5            | 82              | 0.80%           |
| Egypt           | 62299 >10 per 100,000 | 49840 | 303            | 10              | 1646          | 3%              |
| Philippines     | 78500 >10 per 100,000 | 62800 | 382            | 31              | 5103          | 8%              |
| Kenya           | 50809           | 149502          | 115398          | 701             | 30            | 4938            | 4%              |
| Russian Federation | 217696      | N/A             | 174157          | 1058            | 200           | 32922          | 15%              |
| Mexico          | 92701           | 6321            | 77321           | 470             | 180           | 29630          | 38%              |

Projection for the numbers of people requiring pain treatment does not include those with acute pain or pain related to non-terminal cancer or HIV and do not include pain control medications other than morphine. The table is based on an estimate by Foley and others that 80% of terminal cancer patients and 50% of terminal AIDS patients will require an average of 90 days of pain treatment with 60 mg to 75 mg of morphine per day [16]. Country estimates were obtained from INCB website [43]; projections for annual cancer and AIDS deaths are based on the most recent cancer and AIDS mortality figures reported by the WHO [79].

Failure to enact palliative care and pain treatment policies

In 1996, the WHO identified the absence of national policies on cancer pain relief and palliative care as one of the reasons that cancer pain is not adequately treated [46]. In 2000, the organization noted that pain treatment continued to be a low priority in healthcare systems [28] and, again, in 2002 it noted that there was a wide gap between the rhetoric and the reality when integrating palliative care principles into public health and disease control programmes [26].

Although the WHO and leading experts on palliative care have stressed the importance of having a comprehensive strategy [47], most countries do not have palliative care and pain treatment policies, either as stand-alone policies or as part of cancer or HIV/AIDS control efforts [47,48]. Many countries have even failed to add oral morphine and other opioid-based medicines to their list of essential medicines or to issue guidelines on pain management for healthcare workers [42].

The INCB has recommended that national drug control laws recognize the indispensible nature of narcotic drugs for the relief of pain and suffering as well as the obligation to ensure their availability for medical purposes. However, in 1995 only 48% of the governments responding to a survey had laws reflecting the former and 63% the latter [30]. It is not known exactly how many countries still do not use the relevant language in their legislation and even recent model laws and regulations on drug control from the UN Office on Drugs and Crime themselves do not contain these provisions [49-52] (Appendix 1).

Lack of training for healthcare workers

One of the biggest obstacles to the provision of good palliative and pain treatment services in many countries is the lack of training for healthcare workers.
Misinformation about oral morphine is still extremely common among healthcare workers and knowledge of how to assess and treat pain is often very inadequate.

Some of the most common myths maintain that: treatment with opioids leads to addiction; that pain is necessary because it is enables diagnosis; that pain is unavoidable; and that pain has negligible consequences. Each of these myths is inaccurate. Numerous studies have shown that treatment of pain with opioids very rarely leads to addiction [28]; most pain can be treated well [28]; pain is not necessary for diagnosis [23]; and pain has considerable social, economic and psychological consequences as it prevents people who suffer from it, and often their caregivers, from living a productive life [23].

Throughout much of the world, including some industrialized countries, ignorance of the use of opioid medications is the result of a failure to provide healthcare workers with adequate training in palliative care and pain management. A survey by the Worldwide Palliative Care Alliance of healthcare workers in 69 countries in Latin America, Asia and Africa found that 82% in Latin America, 71% in Asia and 39% in Africa had not received any instruction on pain management or opioids during their undergraduate medical studies [53]. Additional studies have documented the significant number of healthcare providers in Africa who report inadequate opportunities for training in palliative care and pain treatment [42]. Even in industrialized countries instruction on palliative care and pain treatment remains a considerable challenge. A 1999 review found that considerable numbers of healthcare workers had insufficient factual knowledge about pain management among cancer patients in the industrialized countries [54] (Appendix 2).

Excessively restrictive drug control regulations or enforcement practices

The 1961 the Single Convention on Narcotic Drugs lays out three minimum criteria that countries must observe when developing national regulations governing the handling of opioids. First, individuals must be authorized to dispense opioids by their professional license to practice or be specially licensed to do so. Secondly, movement of opioids may only occur between institutions or individuals so authorized under national law. Finally, a medical prescription is required before opioids may be dispensed to a patient. Governments may, under the Convention, impose additional requirements if deemed necessary [29].

However, many countries have regulations that go well beyond these restrictions, creating complex procedures for procurement, stocking and dispensing of controlled medications, including: restrictive licensing requirements for health care providers prescribing medicines; cumbersome dispensing procedures; and limitations on the formulation and quantity of medicine that can be prescribed [55]. In some cases, drug control authorities or health systems adopt even more restrictive measures than those required in the formal regulations. Although the diversion of medical opioids from its proper use is frequently cited as the explanation for such policies, the INCB has noted that, in practice, diversion is relatively rare [56] and the WHO has observed that ‘this right [to impose additional requirements] must be continually balanced against the responsibility to ensure opioid availability for medical purposes’ [46].

An example of overly restrictive policies adopted by many countries is to limit the prescription of narcotic pain medicines to medical professionals who qualify for specific licenses. The 1961 the Single Convention on Narcotic Drugs does not require healthcare workers to obtain a special license to handle opioids and the WHO has recommended that ‘physicians, nurses and pharmacists should be legally empowered to prescribe, dispense and administer opioids to patients in accordance with local needs’ [46]. Yet special licenses are common, and nurses and pharmacists are rarely able to prescribe pain medicines. For example, the Worldwide Palliative Care Alliance reported that, in 2007, in Mongolia, Peru, Honduras, Kyrgyzstan and a state in India only palliative care specialists and oncologists are authorized to prescribe oral morphine [53]. In Russia, an AIDS doctor reported that he could not treat a patient who suffered from severe pain because he was not licensed to prescribe morphine and that those oncologists who are would not provide treatment because the patient did not have cancer [57].

Another common obstacle is the special prescription procedures for opioids - for example the use of specific prescription forms and the insistence that multiple copies of the prescription be maintained. The WHO Expert Committee on Cancer Pain Relief has observed that these practices often reduce prescription of opioid pain medicines by 50% or more [46]. In 1995, INCB found that 65% of countries that participated in its survey had special prescription procedures [30].

Another special practice is the requirement that prescriptions by healthcare workers be approved by colleagues or superiors and that dispensing must be witnessed by multiple healthcare workers. In Ukraine, for example, the decision to prescribe morphine has to be made by a group of at least three doctors, one of whom must be an oncologist [58]. In South Africa, two nurses must observe the dispensing of opioids [42].

While the WHO has recommended that ‘decisions concerning the type of drug to be used, the amount of the prescription and the duration of therapy are best made by medical professionals on the basis of the
individual needs of each patient, not by regulation [46], regulations imposing limitations on the dose of oral morphine that can be prescribed per day or the number of days for which it can be prescribed are common. The 1995 INCB survey found that 40% of countries participating set a maximum amount of morphine that could be prescribed at one time to a hospitalized patient and 50% of countries surveyed set limits for patients who lived at home [30]. Limits for home-based patients were frequently less than those for hospitalized patients - in some cases half of the typical daily doses [16]. The survey also found that 20% of participating countries imposed a maximum length of time that a hospitalized patient could receive morphine and 28% had such restrictions for patients at home. In some cases, prescriptions for morphine could not exceed a week's supply; in some countries this was non-renewable [30]. Although no recent comprehensive overview of countries that impose these kinds of limitations is available, they continue to be widespread [53,59].

**Fears of legal sanction**

Although the INCB has recommended that healthcare workers be able to provide opiates without unnecessary fear of legal action for unintentional violations which would inhibit provision or dispensation [60], ambiguity in regulations, poor communication by drug regulators to healthcare workers about the rules for handling opioids, the existence of harsh sanctions (including mandatory minimum sentences) and, in some countries, prosecutions of healthcare workers for unintentional mishandling of opioids, lead to fear among medical professionals. Little research has been published that documents the extent and impact of fears by healthcare providers on the prescription practice globally. A recent survey in the USA of criminal and administrative cases against physicians related to opioid prescription found an increasing trend in prosecutions which has a chilling effect on physician practice [61]. Some authors argue that physicians have an individual obligation to treat patients for severe pain and should be held accountable for a failure to treat pain via a charge of medical malpractice and, in extreme cases, criminal negligence [62].

**Cost**

Although basic oral morphine is inexpensive [16], cost is a frequently cited impediment to improving access to pain treatment and palliative care services, particularly for low and middle income countries. A 2003 study found that the average retail cost of a monthly morphine supply ranged from US$10 in India to US$254 in Argentina [63]. Paradoxically, the study found that median cost of a month's supply of morphine was more than twice as high in low and middle income countries (US$112) as in industrialized countries (US$53). The study suggested that a number of factors might explain the discrepancy: medication subsidies by industrialized countries; industrialized government regulation of the price of opioids; taxes, licenses and other costs related to import of finished product; large overhead of local production; poorly developed distribution systems; low demand; and regulatory requirements that drive up cost. Further, a 2007 report also found that the promotion of non-generic - and costly - forms of opioid analgesics has made pain treatment medications unaffordable in some areas, as inexpensive formulations are withdrawn when more expensive opioids appear on the market [64].

A number of countries have successfully sought ways to create a capacity for the local production of basic oral morphine, in tablet or liquid form, at low cost. For example, in India, a small manufacturing unit has been set up at a hospital that produces low cost immediate release morphine tablets from morphine powder [64]. In Uganda, the ministry of health commissioned charitable procurement and manufacturing facility to produce morphine solution which could be distributed to hospitals, health centres and palliative care providers [65]. In Vietnam, a new opioid prescription regulation allows the ministry of health to mandate state and para-state pharmaceutical companies to produce oral and injectible opioids [66]. These examples illustrate the potential for creating locally manufactured, low-cost oral morphine.

**Health as a human right**

Health is a fundamental human right enshrined in numerous international human rights instruments. The International Covenant on Economic Social and Cultural Rights (ICESCR) specifies that everyone has a right ‘to the enjoyment of the highest attainable standard of physical and mental health’ [67]. The Committee on Economic, Social and Cultural Rights, the treaty’s monitoring body, has held that states must make available and accessible in sufficient quantity ‘functioning public health and health-care facilities, goods and services, as well as programmes’ [68].

As states have different levels of resources, international law does not mandate the kind of health care to be provided and, instead, demands ‘progressive realization’. By committing to the international agreements, a state agrees ‘to take steps... to the maximum of its available resources’ to achieve the full realization of the right to health. High income countries will generally have to provide healthcare services at a higher level than those with limited resources, but all countries will be expected to take concrete steps toward increased services.

The Committee on Economic, Social and Cultural Rights has also held that there are certain core obligations that are so fundamental that states must fulfill them. While resource constraints may justify only partial fulfillment of some aspects of the right to health, the
Committee has observed that ‘a State party cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations...which are non-derogable’. The Committee has identified, among others, the following core obligations: to ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; to provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs; to ensure the equitable distribution of all health facilities, goods and services; and to adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population [68].

**Pain treatment and the right to health**

As morphine and codeine are on the WHO List of Essential Medicines [31], countries have to provide these medications as part of their core obligations under the right to health, regardless of whether or not they have been included on their domestic essential medicines lists [68]. Countries must ensure that they are both available in adequate quantities and physically and financially accessible for those who need them.

Since manufacturing and distribution of controlled medicines, such as morphine and codeine, are completely in government hands, states must put in place an effective procurement and distribution system and create a legal and regulatory framework that enables healthcare providers in both the public and private sectors to obtain, prescribe and dispense these medications. Any regulations that arbitrarily impede the procurement and dispensing of these medications will violate the right to health. States must adopt and implement a strategy and plan of action for the roll out of pain treatment and palliative care services. Such a strategy and plan of action should identify obstacles to improved services as well as take steps to eliminate them.

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States should also regularly measure progress made in ensuring the availability and accessibility of pain relief medications. The requirement of physical accessibility means that these medications must be ‘within sale physical reach for all sections of the population, especially vulnerable or marginalized groups, such as...persons with HIV/AIDS’ [68]. This means that states must ensure that a sufficient number of healthcare providers or pharmacies stock and dispense morphine and codeine and that an adequate number of healthcare workers are trained and authorized to prescribe these medications. Financial accessibility means that, while the right to health does not require states to offer medications free of charge, they must be ‘affordable for all’. According to the Committee, payment for healthcare services must be based on equity and poorer households should not be disproportionately burdened by cost [68].

Countries also have an obligation to progressively implement palliative care services, which, according to the WHO, must have ‘priority status within public health and disease control programmes’ [26]. Countries must ensure an adequate policy and regulatory framework, develop a plan for the implementation of these services and take all steps that are reasonable within available resources to execute the plan. Failure to attach adequate priority to developing palliative care services within healthcare services will violate the right to health [55].

**Pain treatment and the right to be free from cruel, inhuman and degrading treatment**

The right to be free from torture, cruel, inhuman and degrading treatment or punishment is also a fundamental human right that is recognized in numerous international human rights instruments [69-75]. This right creates a positive obligation for states to protect persons in their jurisdiction from torture, cruel, inhuman and degrading treatment or punishment. In a letter to the Chairperson of the 52nd Session of the Commission on Narcotic Drugs, the UN Special Rapporteur on Torture, Cruel, Inhuman and Degrading Treatment and Punishment and the UN Special Rapporteur on the Right to Health noted that governments’ failure to take measures to ensure the accessibility of pain treatment threatens this fundamental right [75].

**Summary**

The lack of pain treatment medicine is both perplexing and inexcusable. Pain causes terrible suffering yet the medications to treat it are cheap, safe, effective and generally straightforward to administer. Furthermore, international law obliges countries to make adequate pain medications available. Over the last 20 years, the WHO and the INCB have repeatedly reminded states of this obligation. However, little progress has been made and tens of millions of people continue to suffer - both directly from untreated pain and from its consequences.

Under international human rights law, governments must take steps to ensure that people have adequate access to treatment for their pain. At a minimum, states must ensure the availability of morphine, the mainstay medication for the treatment of moderate to severe pain. Failure to make essential medicines such as morphine available or, more broadly, to take reasonable steps to make pain management and palliative care services accessible to all, results in a violation of the right to health. In some cases, failure to ensure patients have access to treatment for severe pain will also give rise to a violation of the prohibition of cruel, inhuman and degrading treatment.

There are many reasons for the enormity of the gap between pain treatment needs and what is delivered, but the chief among them is a willingness by many governments around the world to passively stand by as people...
suffer. Excessive over-regulation by governments and the ignorance of healthcare providers conspire to create a vicious cycle of under-treatment. As pain treatment and palliative care are not priorities for the government, healthcare workers do not receive the necessary training in order to assess and treat pain. This leads to widespread under-treatment and to a low demand for morphine. Similarly, complex procurement and prescription regulations, and the threat of harsh punishment for mishandling morphine, discourage pharmacies and hospitals from stocking and healthcare workers from prescribing it, which again results in low demand. A lack of the prioritization of opioid pain medicine is not a result of the low prevalence of pain but of the invisibility of its sufferers.

To break out of this vicious cycle, individual governments and the international community must fulfill their obligations under international human rights law. Governments must take action to eliminate barriers that impede the availability of pain treatment medications. They must develop policies on pain management and palliative care; introduce instruction for healthcare workers, including for those already practicing; reform regulations that unnecessarily impede the accessibility of pain medications; and take action to ensure their affordability. While this is a considerable task, various countries, such as Uganda and Vietnam, have shown that such a comprehensive approach is feasible in low and middle-income countries. Other nations must learn from these experiences and work towards the realization of full access to pain relief medicines.

Appendix 1: Uganda case study
In 1998, Ugandan government officials, representatives of non-governmental organizations and the WHO agreed on ways in which pain treatment could be made available to the population. These steps included: developing national palliative care, cancer and AIDS pain relief policies; implementing a training course to complement existing palliative medicine teaching and increasing the number of skilled providers; developing new drug regulations: updating the essential drug list; conducting estimates of the medical need for morphine; and requests from the drug control authority for an increased national allowance from the INCB [77].

Following this agreement, Uganda has made considerable progress in reducing or eliminating barriers that have traditionally impeded access to pain treatment medications. In its 5-year Strategic Health Plan for 2000-2005, the government noted that palliative care was an essential clinical service for all Ugandans and so became the first nation in Africa to do so. It also added liquid morphine to its essential drug list, adopted a new set of guidelines for the handling of class A drugs for healthcare practitioners - also a first in Africa - and authorized the prescribing of morphine by nurses who have been trained in palliative care. By early 2009, 79 nurses and clinical officers had received training in pain management and been authorized to prescribe oral morphine, several thousand healthcare workers had attended a short course on pain and symptom management and 34 out of 56 districts in Uganda had oral morphine available and in use [65]. Despite this impressive progress, many challenges remain, including: ensuring the availability of oral morphine throughout Uganda; keeping it affordable; preventing stockouts; and training all relevant healthcare workers.

Appendix 2: Vietnam case study
Since 2005, Vietnam has made considerable progress in expanding access to palliative and pain treatment services. A working group on palliative care, including health officials, physicians and NGOs, conducted a rapid situation analysis devised to assess the availability of, and need for, palliative care in Vietnam. This rapid analysis found severe chronic pain to be common among cancer and HIV/AIDS patients, while the availability of opioid analgesics was severely limited, palliative care services were not readily available and clinicians lacked adequate training [78]. The working group recommended that national palliative care guidelines be developed, a balanced national opioid control policy be designed, training for healthcare workers be expanded and that the availability and quality of palliative care services be improved.

In 2006, the Ministry of Health issued detailed guidelines to practitioners on palliative care and pain management and, in 2008, it issued new guidelines on opioid prescription which have eased a number of key regulatory barriers. The Ministry has also approved a package of training courses for practicing physicians and two medical colleges now offer instruction on palliative care to undergraduate medical and nursing students. However, only a few hundred healthcare workers have received training so far, understanding of palliative care among healthcare officials continues to be limited, various regulatory barriers persist and few pharmacies and hospitals stock oral morphine.

Acknowledgements
The authors would like to thank Katherine Todrys, Seth Davis, Olena Baev, Emily Dauria and Mignon Lamia for their help with the development of the article and all those working to provide palliative care worldwide for their dedication and compassion.

Authors’ contributions
DL and JJA conceived the article and reviewed the existing literature. DL wrote the article and RS and JJA reviewed and contributed to a revised version. All authors reviewed and approved the final text.
Competing interests
The authors declare they have no competing interests. This research was
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Access to many medicines controlled under international drug control treaties is lacking around the world, with the exception of a few industrialized countries. Even in some highly industrialized countries access is limited. The realization of the Millennium Development Goal 8e, “Provide access to affordable essential drugs in developing countries”, is likely to be further away for opioid analgesics than for any other class of medicines.

These controlled medicines are used to treat conditions including:

- Moderate to severe pain
- Opioid dependence
- Obstetric complications

Pain Management

The World Health Organization (WHO) estimates that 5 billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain.¹

In these countries, each year tens of millions of patients are suffering without adequate treatment:

- 1 million end-stage HIV/AIDS patients
- 5.5 million terminal cancer patients
- 0.8 million patients suffering injuries, caused by accidents and violence
- Patients with chronic illnesses
- Patients recovering from surgery
- Women in labour (110 million births each year)
- Paediatric patients

Opioid dependence treatment and HIV-prevention

Despite strong evidence of efficacy, adequate treatment of opioid dependence such as oral substitution therapy is frequently unavailable.

There are 16 million people who inject drugs in the world.² Of the new HIV infections in Eastern Europe and Central Asia in 2005, 67% were due to injection drug use.³ It is estimated that if pharmacological treatment of opioid dependence was to be made readily available, such access could result in the prevention of up to 130,000 new HIV infections from needle sharing outside sub-Saharan Africa annually. A meta analysis of four studies showed a reduction of annual HIV-seroconversion by 64% (C.I. 34 - 81 %).⁴ Such treatment would also reduce the spread of hepatitis C and other blood-borne diseases as well as decrease deaths from opioid overdose by 90%.⁵

Finally, it is estimated that every dollar invested in treatment of opioid dependence has a 3 to 13-fold return to society.

Maternal death

Each year, half a million women die during childbirth⁶, about 120,000 of them from post-partum bleeding.⁷ Many of these lives could have been saved if medicines to stop the bleeding were available.

Treatment is simple and inexpensive

Moderate to severe pain can be easily controlled with opioid analgesics such as morphine. Opioid dependence can be effectively treated with oral substitution therapy using methadone or buprenorphine. While post-partum bleeding can be treated by either ergometrine or oxytocin, these medicines are both not readily available. Of the two medicines, ergometrine is a controlled substance.

Lack of access affects all controlled medicines on the WHO Model List of Essential Medicines. Because of their status as essential medicines, their availability for
medical treatment is a human right, as defined in the International Covenant on Economic, Social and Cultural Rights (article 12, the Right to Health).

**Balancing prevention and medical availability**

Many factors contribute to the lack of access to controlled medicines. There is a need for greater awareness among policy makers, healthcare professionals and the general public to dispel the myth that opioid analgesics (i.e. pain killers derived from opium, such as morphine) will do harm to patients and cause dependence. The fear of dependence upon pain treatment is largely unfounded, as almost all patients are able to stop their opioid medication at the end of their treatment with no long-lasting effects. Although substitution treatment does not terminate dependence, it removes most of the detrimental health effects for the patient as well as the harmful impact of drug dependency on a society. Ergometrine, a medicine used in obstetrics, is often unavailable for use in childbirth. Although not a drug of abuse it can be used as a starting material for the synthesis of such drugs.

Of course, the risk of dependence through non-medical use is real and society needs to protect against these drugs being diverted from appropriate medical use. This can and should be done in a balanced way that does not affect their availability for appropriate medical treatment.

**What has been done so far?**

In response to the World Health Assembly and the United Nations’ Economic and Social Council in 2005, WHO developed the Access to Controlled Medications Programme (ACMP) in consultation with the International Narcotics Control Board and a number of NGOs. The strategy was presented to and accepted by the UN’s Commission on Narcotic Drugs and the World Health Assembly in 2007. The ACMP focuses on lifting barriers that impede access to controlled medicines, including opioids - the most important category of these medicines.

The ACMP has participated in activities of other organizations directed at lifting these barriers and started the development of pain treatment guidelines. Over the past years, ACMP has raised awareness about the problem of access to these medicines through presentations at conferences, publications and the media.

**What needs to be done?**

The ACMP will address all aspects that act as barriers to obtaining controlled medicines for medical treatment including: legislative and administrative procedures, as well as knowledge among policy makers, healthcare workers, patients and their families.

During the first phase (six years) of its implementation, the ACMP focus is on identifying the most effective assistance mechanisms and further developing tools to be used in the programme. The ACMP’s activities will include:

- **Normative guidance**
  - Development and dissemination of internationally recognized standards for treatment and policy guidelines

- **Policy analysis**
  - Workshops for healthcare professionals, legislators and law enforcers to analyse and discuss the problem and draft national action plans for its resolution
  - Improving access to effective treatment by reviewing legislation and administrative procedures

- **Training and practical assistance**
  - Supporting implementation of action plans at the national level
  - Training healthcare professionals through workshops on rational prescribing, provision of information materials and curriculum review support to universities
  - Training workshops for civil servants to make realistic estimates of future needs for opioid analgesics and to compile reliable statistics, and
  - Training workshops on procurement for pharmaceutical inspectors and law enforcement

- **Further study**
  - Performing surveys on accessibility, availability, affordability and use of the medicines and substances involved.
Who are our partners?

The ACMP supports governments in identifying and overcoming obstacles that hinder the procurement and distribution of controlled medication to help ensure adequate availability of opioid analgesics for pain treatment and opioid dependence. WHO will work with national authorities, including regulatory authorities, public health administrators and law enforcement officials. WHO will also draw on the expertise of relevant WHO departments and units involved in diseases related to pain, international and national experts in the area of opioid medication, WHO Collaborating Centers, the International Narcotics Control Board and healthcare professionals, such as medical practitioners, nurses with special training and pharmacists. Work in countries will be implemented in close collaboration with WHO regional offices and WHO Representatives in the countries.

"The ACMP is an extremely important development which will have a similar major impact on the management of severe unrelieved pain worldwide as the 1986 WHO initiatives on the management of cancer pain."

International Association for the Study of Pain

The ACMP’s current partners and endorsers include national and international healthcare experts, WHO Collaborating Centre for Policy and Communications in Cancer Care at the University of Wisconsin and national and international professional associations, such as the United States’ Cancer Pain Relief Committee, the International Harm Reduction Association (IHRA), the International Association for the Study of Pain (IASP), the European Association for Palliative Care (EAPC), the African Palliative Care Association (APCA), the International Association for Hospice and Palliative Care (IAHPC) and the International Observatory for End of Life Care.9

To develop activities in twelve East European countries, ACMP formed the ATOME-consortium (Access to Opioid Medicines in Europe) which includes: the European Association for Palliative Care (EAPC), the Eurasian Harm Reduction Network, Help the Hospices UK, Hospice Casa Sperarantei, the International Observatory for End of Life Care at the University of Lancaster, Ministry of Interior and Administrative Reform - Government of Romania, National Anti-Drugs Agency and NautaDutilh NV.

The governments of France and the Netherlands as well as the US Cancer Pain Relief Committee, the Open Society Institute and IASP, are donors to the Programme. The European Commission (Directorate-General for Research) is a donor to the ATOME consortium through its 7th Framework Programme.

What will happen as a result?

Expected outputs of the ACMP include internationally recognized standards for clinical treatment with controlled medications, tools and national capacity to assess trends in opioid availability and future needs of controlled medicines, a review of national policy and legislation on controlled medicines, national healthcare workers trained in rational use of controlled medicines, and curriculum developed on the use of controlled medications.

The direct beneficiaries of the ACMP will be national authorities such as regulatory authorities, national healthcare administrators, healthcare professionals and law enforcement officials in developing countries where access to pain medication is severely limited. The indirect and ultimate beneficiaries of the ACMP will be people in need of controlled medication, particularly patients suffering from cancer, chronic pain, diabetic neuropathy, HIV neuropathy, sickle-cell disease, pre-and post-operative surgery pain, traumatic pain, women in delivery, neonates, children, particularly paediatric patients in developing countries, as well as patients with opioid dependence and their communities.

The ACMP is the first and only global initiative in this field adding value to national
processes through the provision of evidence-based guidelines, policy analysis, training and practical assistance. The clinical guidelines, tools and training materials developed under the programme will provide universal and internationally recognized standards for the clinical use of controlled medicines for use by national governments.

**Proposed budget**

The ACMP’s action plan has a projected budget of US$ 55.5 million for its first six years (inclusive 13% Programme Support Cost). Two-thirds of the budget will focus on policy development and support activities to improve access to opioids for pain management. The remaining third will be directed towards substitution therapy efforts. It is expected that half of the budgeted activities will be delivered through the regional and country offices\(^1\), while the remainder of the budget will support ACMP work at WHO headquarters (including 11% for staff).

Contributions from governments as well as NGOs are urgently needed.

**Further information**

More information on the Framework of the Access to Controlled Medications Programme, the nature of access barriers for controlled medicines, as well as literature references, is available on the WHO Medicines web site: http://www.who.int/entity/medicines/areas/quality_safety/sub_Int_control/en/index.html

\(^1\) The countries with low or no access are defined as countries where the consumption of opioid analgesics is lower than 30% of the adequate per capita consumption. The adequate consumption is defined as the average per capita consumption in the top 20 countries in the Human Development Index.


National Strategies
National Pain Strategy

Pain Management for all Australians

Developed by the National Pain Summit initiative
www.painsummit.org.au

Led by:
Australian and New Zealand College of Anaesthetists
Faculty of Pain Medicine
Australian Pain Society
Chronic Pain Australia

In collaboration with inaugural supporters:
MBF Foundation
University of Sydney Pain Management Research Institute
Strategic Action Plan

Mission

To improve quality of life for people with pain and their families, and to minimise the burden of pain on individuals and the community.

Goal 1: People in pain as a national health priority

Recognition and optimal management for people in pain will be pursued as a national health priority. This includes people experiencing acute pain, sub-acute pain, chronic pain and pain associated with cancer.

The economic cost of sub-optimal management of pain will be reduced, for people with pain, carers, families and the community.

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<tr>
<th>Goal 1: Pain as a national health priority</th>
<th>Strategic actions</th>
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<tbody>
<tr>
<td><strong>Objectives</strong></td>
<td><strong>Strategic actions</strong></td>
</tr>
<tr>
<td>1 Establish a national body involving all stakeholder groups to identify partnerships, framework and resources required to build capacity and deliver proposed outcomes</td>
<td>1.1 Develop a charter/terms of reference, structure and funding model, and governance structures</td>
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<td>1.2 Implement a strategy of charting pain as the ‘fifth vital sign’ in all health facilities in the nation, recorded at every consultation and in all communications between practitioners, along with appropriate monitoring for adverse effects (especially sedation), of pain medicines and other treatments</td>
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<td>1.3 Develop advocacy strategy to incorporate pain into all national health care policies and reform initiatives</td>
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<td>2 De-stigmatise the predicament of people with pain, especially chronic non-cancer pain</td>
<td>2.1 Develop a community awareness campaign (including professionals in health and education) to - change attitudes towards people with pain - raise awareness of physical, psychological and environmental factors</td>
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<td>2.2 Promote education and training for health professionals to improve understanding of the multifaceted nature of pain</td>
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<td>2.3 Deliver tailored training in chronic pain management for employment and insurance organisations, and for teachers and counsellors in the education system managing paediatric and adolescent patients</td>
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*High priority*
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<th><strong>Goal 1:</strong> Pain as a national health priority</th>
<th><strong>Strategic actions</strong></th>
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<tr>
<td><strong>Objectives</strong></td>
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<tr>
<td>3 Achieve federal and state government recognition of chronic pain as a chronic disease in its own right</td>
<td>3.1 Develop advocacy strategy</td>
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<td>3.2 Assess burden of chronic pain in children, adolescents and adults upon acute care system through changing coding focus to allocate a higher priority to collating chronic pain diagnoses in the inpatient population, using the Australian Coding Standards for disease and health intervention classification (ICD-10-AM and ACHI). In addition, develop a system for collating chronic pain diagnoses for outpatient populations</td>
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<td>3.3 Recognise the critical role of adequate management of acute pain, and early recognition of patients at risk of developing chronic pain, to minimise the risk of acute pain progressing to chronic pain</td>
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<td>3.4 Recognise the burden of pain in residential aged care facilities, and improve the quality of end-of-life care, by adjustments to the funding instrument</td>
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<td>3.5 Streamline provision of, and ensure uniform access to, medicines with evidence of benefit in ameliorating pain or preventing transition from acute to chronic pain, through appropriate funding of hospital pharmacies and the Pharmaceutical Benefits Scheme</td>
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<td>3.6 Recognise chronic pain as a disease category in the Employment Services System database of the Department of Education, Employment and Workplace Relations, to assess need for services in specific areas</td>
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<td><strong>High priority</strong></td>
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<tr>
<td>4 Reduce the economic cost to people with pain, carers, families and the community of sub-optimal management of pain</td>
<td>4.1 Implement strategies to increase return to work rates for both work related and non-work related injuries</td>
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<td>4.2 Develop skills in health professionals to understand the management of pain in a work related environment</td>
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</table>
Goal 2: Knowledgeable, empowered and supported consumers

People with pain, their carers and other supporters will have the knowledge and confidence to seek appropriate advice, education and/or treatment to enable them to better understand and manage their pain.

The social, economic and regulatory environment (i.e. employers, legal systems, compensation systems, insurance bodies, and government agencies) will provide a compassionate, empathic and well-informed framework to support people in pain.

Educational and management initiatives for people with pain, carers and other supporters will be developed and evaluated in collaboration with consumers and carers.

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<th>Objectives</th>
<th>Strategic actions</th>
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| 5 Improve community understanding of the nature of chronic pain and best-practice management | 5.1 Improve the availability of education and information materials for consumers, carers and other supporters, health workforce, insurers/case managers, employers and employees (including multimedia materials and age-appropriate materials for children and adolescents), to improve understanding of  
  - management of acute pain and sub-acute pain  
  - biological differences between acute and chronic pain, and implications for management  
  - how to reduce the risk of chronic pain  
  - best-practice management for chronic pain  
  - management of pain medicines  
  - where to go for appropriate health care services |
| 5.2 Establish community adult education programs | |
| 5.3 Promote programs for children and adolescents that include school and parents | |
| 5.4 In collaboration with appropriate experts and organisations, ensure specific programs and materials consider the special needs of infants, older adults, people with a history of substance abuse, people with disabilities (including learning disabilities), people of diverse cultural and linguistic backgrounds, Indigenous people, and carers and other supporters | |
### Goal 2: Knowledgeable, empowered and supported consumers

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<th>Strategic actions</th>
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| 6. Provide easily accessible information and support programs to assist people with pain, carers and other supporters, and practitioners to understand and be more proactively involved in managing pain **High priority** | 6.1 Put a submission to government for national, community-based, staff-led self-management education and support programs, available to people with pain, carers and other supporters and appropriate to life stage (international examples are the Pain Association Scotland, UK Expert Patients Programme and the Calgary ‘Living Well’ Program)\(^{128}\)  
6.2 Provide toolkits and follow-up coaching for self-management support and reinforcement of skills/behaviour change  
6.3 Provide evidence-based consumer information to assist treatment/management decisions  
6.4 Provide practical support for people with pain in continuing their usual work, school and family activities and maintaining independence  
6.5 Provide pain diaries and passports (multilingual) for patients with chronic pain, patients diagnosed with cancer, or when a palliative approach (for non-malignant disease) is adopted  
6.6 Support key consumer groups to provide resources, advice and community-based support for people with chronic pain, carers and other supporters, in line with National Pain Summit aims and recommendations  
6.7 Establish a national network of pain hotlines for consumers, carers and other supporters, and primary care practitioners  
6.8 Conduct a survey/environment scan of accredited pain services, support organisations, websites and resources (including resources for pain in cancer and palliative care), and evaluate which provide evidence-based services  
6.9 Establish a centralised website with links to quality services, information and resources as identified in 6.8 (An existing directory of medical pain services directory is on the website of the Australian Pain Society. Cancer pain and palliative care resources could also be made available via evIQ or Caresearch. Website should not be limited to medical services.)  
6.10 Establish networks with consumer groups where pain issues are common, e.g. National Seniors, Carers Australia, Parkinson’s disease, Alzheimer’s disease and multiple sclerosis |
## Goal 2: Knowledgeable, empowered and supported consumers

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<tr>
<th>Objectives</th>
<th>Strategic actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Support and empower people with pain, carers and other supporters in interactions with insurers</td>
<td>6.11 Promote national distribution of standardised patient and carer education materials (e.g. <em>Overcoming Cancer Pain</em>, Cancer Council NSW)</td>
</tr>
<tr>
<td>7.1 Establish ombudsman for personal injury insurance</td>
<td>7.2 Provide materials to inform people with pain, carers and other supporters in their interactions with insurers</td>
</tr>
<tr>
<td>8 Empower consumers to make choices about their end-of-life pain management and care through advance care planning</td>
<td>8.1 Promote uptake of advance care planning, in partnership with and supported by the health system</td>
</tr>
</tbody>
</table>
Goal 3: Skilled professionals and best-practice evidence-based care

People with pain will have timely access to best-practice, evidence-based assessment and care.

Comprehensive education and training in pain management will give medical, nursing and allied health professionals in the public and private sectors the knowledge and resources to deliver such care. Education in the biological processes underpinning acute and chronic pain will give health professionals an accurate conceptualisation of pain and underpin care.

Consumer expertise will be included in the development of professional education materials.

At the end of their lives, all Australians will die with their preventable pain and other symptoms well managed, in the place of choice for them and their families.

Goal 3: Skilled professionals and evidence-based care

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<tr>
<th>Objectives</th>
<th>Strategic actions</th>
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<tr>
<td>9</td>
<td>Validate and implement a brief universal standardised screening/assessment tool (or tools) for pain, including</td>
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<tr>
<td>9.1</td>
<td>- pain as 5th vital sign i.e. pain intensity charting</td>
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<td></td>
<td>- detailed pain history (site, radiation, intensity, character etc)</td>
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<td></td>
<td>- standardised instruments for pain type diagnosis and assessment of yellow and red flags¹²⁹</td>
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<td></td>
<td>- effects of pain on societal level (e.g. blue and black flags)¹³⁰</td>
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<td></td>
<td>- planning for pain management prior to surgery</td>
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<td></td>
<td>- pain assessment following surgery, injury or painful intervention and for appropriate medical patients (intensity and type of pain, and effects of pain on mental and physical function)</td>
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<td></td>
<td>- careful follow-up after surgery, injury or painful intervention</td>
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<td></td>
<td>- recording of severe uncontrolled pain above a designated duration as morbidity in hospital outcome data</td>
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<td></td>
<td>- recording of significant persisting pain as a hospital discharge category requiring a follow-up plan in discharge record</td>
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<td></td>
<td>- to apply to all patients, whether medical, surgical or cancer patients, regardless of age and language barriers</td>
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<td></td>
<td>- appropriate monitoring to enable safe titration of pain relief for individual patients</td>
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<td></td>
<td>- stratifying risk for abuse when initiating opiates</td>
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High priority
### Goal 3: Skilled professionals and evidence-based care

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<tr>
<th>Objectives</th>
<th>Strategic actions</th>
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</table>
| 9.2        | Survey and promote existing evidence-based decision support and information systems, and develop new systems where needed, such as:  
  - online tools e.g. MAP of Medicine  
  - dose calculators  
  - treatment protocols  
  - advice (passive or active) e.g. professional hotline, GP liaison staff in pain clinics, acute pain services in hospitals for advice on acute pain management, prevention and early management of chronic pain  
  - information about authority scripts and the palliative care section of the PBS  
  - mechanisms to ensure decision support and information systems are updated as the evidence base changes |
| 9.3        | In collaboration with professional bodies and educators, designate pain management as a key competency in undergraduate and postgraduate education for medical, nursing and allied health workforce, and develop a national pain management curriculum, including teaching the scientific differences between acute, chronic and cancer pain (This could link with successful national educational initiatives e.g. palliative care curriculum for undergraduates and EdCaN (National Cancer Nursing Education Program)) |
| 9.4        | Develop incentives and remove disincentives for upskilling and accreditation |
| 9.5        | Promote CPD in pain assessment and management across clinical groups, including:  
  - workers in the community, hospitals and residential care facilities  
  - health care providers in cancer and palliative care settings  
  - health care providers involved in post-surgical care  
  - those caring for people with special needs including dementia  
  - complementary practitioners  
  Note the need for a comprehensive strategy with targeted messages for different groups of providers and different settings. Implementation ‘products’ should be sustainable and recognise that in some settings (such as aged care facilities), staff turnover may be high. Materials should be accessible through existing websites for health professionals e.g. Caresearch, Cancer Learning, eviQ. |
<p>| 9.6        | Implement advanced-skill training and accreditation in pain management for health professionals, rehabilitation providers, aged care providers and Independent Medical Examiners of WorkCover and Third Party patients\textsuperscript{131} |</p>
<table>
<thead>
<tr>
<th>Goal 3: Skilled professionals and evidence-based care</th>
<th>Strategic actions</th>
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<tr>
<td><strong>Objectives</strong></td>
<td><strong>Strategic actions</strong></td>
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<tr>
<td>9.7 Provide a toolkit for primary care practitioners, including template pain management plan</td>
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<td>9.8 Provide a directory to inform health practitioners of existing resources, e.g. accredited pain providers in local area (see also 6.9)</td>
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<td>9.9 Promote training in interdisciplinary/interprofessional practice and joint meetings of professional organisations</td>
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<tr>
<td>9.10 Develop equivalent education, training, tools and competencies for paediatric pain management</td>
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<tr>
<td>10 Establish and promote systems and guidelines to ensure adequate management of acute, chronic and cancer pain</td>
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<td><strong>High priority</strong></td>
<td><strong>Strategic actions</strong></td>
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<tr>
<td>10.1 In collaboration with professional bodies and consumers, define core competencies in pain management required across clinical groups, care settings, and levels of professional practice</td>
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</tr>
<tr>
<td>10.2 In collaboration with professional bodies, government, educators and managers, establish and promote resources to support professional competencies, including resources described in 9.1 and 9.2 relevant clinical guidelines</td>
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<tr>
<td>10.3 Define role of pharmacists in maximising effectiveness of medicines and minimising unwanted effects of pain medicines across care settings, evaluate benefits and resource pharmacist role</td>
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<tr>
<td>10.4 Promote practitioner awareness and active use of Acute Pain Management: Scientific Evidence</td>
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<tr>
<td>10.5 Promote use of existing clinical guidelines for chronic pain (including generic palliative care and cancer care), and establish and promote Australian pain management guidelines for aged care and palliative care in the community (including special guidelines where needed such as for people with dementia)</td>
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</tr>
<tr>
<td>10.6 Assess evidence base for comprehensive Australian clinical guidelines for chronic pain and cancer pain, and develop research agenda to fill gaps</td>
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<tr>
<td>10.7 Support ‘Pain partnership in cancer and palliative care’ group for two years to identify and review available resources create a series of implementation activities utilise existing networks and organisation focus on changing attitudes to pain foster clinical, research and education relationships between pain medicine and palliative care services, including paediatric services</td>
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<tr>
<td>Goal 3: Skilled professionals and evidence-based care</td>
<td>Strategic actions</td>
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<tr>
<td>11 Increase the available workforce for pain management and palliative care</td>
<td>11.1 Identify needs for increased workforce for pain management and palliative care</td>
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<tr>
<td></td>
<td>11.2 Train additional health professionals in Pain Medicine and Palliative Care</td>
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</table>
Goal 4: Access to interdisciplinary care at all levels

*People with pain will have timely access to effectively coordinated care and support, as close as possible to where they live.*

*People with pain will have access to an interdisciplinary team of appropriately skilled practitioners, (virtual or actual), both in community and in hospital settings.*

*Health services for people with pain will be developed and evaluated in collaboration with consumers.*

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<thead>
<tr>
<th>Objectives</th>
<th>Strategic actions</th>
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<tbody>
<tr>
<td>12.1</td>
<td>Bring together all stakeholders to conduct an environmental analysis, define components of an evidence-based model for the primary health care sector (including pain management for chronic pain and for cancer and palliative care patients), and identify funding gaps</td>
</tr>
<tr>
<td>12.2</td>
<td>Identify and advocate for appropriate funding sources, potentially including:</td>
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<tr>
<td></td>
<td>- new Medicare item numbers (linked to accreditation) for interdisciplinary assessment and management of pain, allowing:</td>
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<td></td>
<td>&gt; longer consultations where needed, especially for complex patients</td>
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<td></td>
<td>&gt; group meetings to discuss management and agree management plan</td>
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<td></td>
<td>&gt; preparation of written care plan (signoff by GP)</td>
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<td></td>
<td>&gt; reimbursement of nursing and allied health care at a level adequate to achieve agreed outcomes</td>
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<td></td>
<td>&gt; reimbursement for communication between practitioners</td>
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<td></td>
<td>&gt; primary health care professionals conducting group self-management programs</td>
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<td></td>
<td>&gt; reimbursement of evidence-based complementary interventions by accredited practitioners</td>
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<td></td>
<td>- public funding of community-based clinics</td>
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<td></td>
<td>- funding of accredited interdisciplinary cognitive behavioural therapy programs for appropriate candidates</td>
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<td></td>
<td>- funding of community/peer educators</td>
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<td></td>
<td>- systematic regional/statewide resourcing</td>
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</tbody>
</table>

*High priority*
### Goal 4: Access to interdisciplinary care at all levels

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Strategic actions</th>
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<tr>
<td></td>
<td>funding for practitioner training and rotations, including more training positions in specialist pain clinics across clinical groups</td>
</tr>
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<td></td>
<td>review of Medicare item numbers for comprehensive geriatric assessment to ensure pain is listed as an important component</td>
</tr>
<tr>
<td>12.3</td>
<td>Implement a triage procedure/tool to identify appropriate referral according to complexity and other factors</td>
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<tr>
<td>12.4</td>
<td>Provide access to acute pain services or advice at an appropriate level in community and hospital settings, to improve management of acute pain, help identify patients at risk of chronic pain, initiate measures to reduce the risk of development of chronic pain, and ensure early management of chronic pain</td>
</tr>
<tr>
<td>12.5</td>
<td>Establish interdisciplinary clinical networks to foster regional relationships and collaboration between primary care providers, relevant specialists (not just pain specialists), specialist pain units, palliative care services and aged care services, including:</td>
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<tr>
<td></td>
<td>– consumer involvement to ensure consumer-focused care</td>
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<td></td>
<td>– access for older people to attend multidisciplinary pain clinics when necessary</td>
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<td></td>
<td>– access for general practitioners to palliative care specialists, under agreed referral and access criteria</td>
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<tr>
<td></td>
<td>– access to nurses who can administer opioids when necessary</td>
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<tr>
<td>12.6</td>
<td>Consider comorbidities and dovetail with other services where needed, including other chronic disease, cancer care, palliative care, aged care, rehab, mental health, drug and alcohol</td>
</tr>
<tr>
<td>12.7</td>
<td>Promote novel models of service provision and evaluation, such as video/teleconferencing and telehealth services in rural and remote areas (including services between primary health care providers and specialists)</td>
</tr>
</tbody>
</table>
| 12.8       | Develop a new interdisciplinary role of accredited pain educator, which is upskilled in both physical and psychological domains (not a new discipline, but an accredited role that could be performed by any health professional with training, knowledge and skills)"
### Goal 4: Access to interdisciplinary care at all levels

<table>
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<tr>
<th>Objectives</th>
<th>Strategic actions</th>
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<tbody>
<tr>
<td>12.9 Facilitate co-location of practitioners where possible, for example by expanding the current model of the subsidised Mental Health Nurses Scheme to include an allied health professional to be employed on-site in general practices</td>
<td></td>
</tr>
</tbody>
</table>
| 13 Ensure meaningful communication about pain management between practitioners and patients, and between practitioners **High priority** | 13.1 Develop systems, including e-Health records and care pathways, to facilitate  
  - improved communication between patients and health professionals  
  - improved communication between multiple care providers  
  - patient and carer-centred care  
  - improved information sharing on transition from one care setting to another  
  13.2 Establish communication channels, e.g. teleconference team meetings if at different sites  
  13.3 Promote continuity of care for people with pain  
  13.4 Promote communication with other specialists who deal with people in pain and among the broader community of health professionals |
| 14 Expedite access to Tier 1 Multidisciplinary Pain Clinics (as defined by the Australian Pain Society) for people with more complex problems | 14.1 Provide care in the community for the majority of people with pain (see objective 12) to free up specialist services  
  14.2 Implement triage criteria for referral to multidisciplinary pain clinic, including a ‘traffic light’ approach to readily identify refractory cancer pain that needs early referral to pain clinic (or specialist palliative care unit)  
  14.3 Develop discharge criteria for referral to care in the community following attendance at a multidisciplinary pain clinic  
  14.4 Ensure adequate numbers of medical specialists, nurses and allied health professionals in multidisciplinary pain clinics  
  14.5 For each major population centre (e.g. 0.5-1 million), designate at least one tier 1 pain medicine centre and one level 3 inpatient palliative care unit to be responsible for:  
  - complex pain assessments  
  - training in patient selection and peri-procedure care of common interventional pain techniques applicable in cancer e.g. intrathecal catheters, cordotomy, coeliac plexus and other nerve blocks |
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<tbody>
<tr>
<td><strong>Goal 4: Access to interdisciplinary care at all levels</strong></td>
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<tr>
<td><strong>Objectives</strong></td>
<td><strong>Strategic actions</strong></td>
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</table>
| 15 Ensure tertiary specialist pain clinics have resources needed to support key strategies | 15.1 Fund tertiary specialist pain clinics to:  
- continue to care for people with complex needs  
- set standards for best-practice clinical care  
- evaluate and develop new treatment options  
- refine referral criteria for people needing high level treatment  
- provide support, education and training in assessment and management of people with chronic pain to primary care practitioners in all categories, and specialists across the spectrum of specialisations  
- provide pain education at undergraduate level and postgraduate level, including other specialist medical training schemes  
- develop and maintain basic and clinical research programs to provide new treatments for chronic pain  
- maintain links with primary and secondary care to sustain a cost-effective, comprehensive system for managing chronic cancer and non-cancer pain  
- enable access to specialist pain management via outreach programs for people who are unable to attend clinics |   |
| 16 Develop equivalent strategies for access for interdisciplinary care for children and adolescents in all of the above domains | 16.1 See above. In particular, note the need for planning of transitional care for children transferring ongoing care to adult care settings. |   |
Goal 5: Quality improvement and evaluation

Outcomes in pain management will be enhanced through a quality improvement process using measurement of outcomes, evaluation and feedback.

The health care system will facilitate the judicious, appropriate, safe and effective use of pain medicines and technologies, and other pain management strategies.

Quality improvement and evaluation initiatives for people with pain will be developed in collaboration with consumers.

<table>
<thead>
<tr>
<th>Goal 5: Quality improvement and evaluation</th>
<th>Strategic actions</th>
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<tbody>
<tr>
<td>Objectives</td>
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</tr>
<tr>
<td>Ensure quality use of medicines for pain</td>
<td>Develop and promote use of guidelines for quality use</td>
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<tr>
<td>management in the community and improve</td>
<td>of pain medicines in the community, including for</td>
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<tr>
<td>systems to detect and manage unsanctioned</td>
<td>palliative and end of life care in the community^{135}</td>
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<tr>
<td>use</td>
<td>Develop a national real-time monitoring and auditing</td>
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<td></td>
<td>system for opioid prescriptions and codeine</td>
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<td>containing products, to identify inappropriate</td>
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<tr>
<td></td>
<td>prescription and unsanctioned use</td>
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<tr>
<td>17 High priority</td>
<td>Provide joint review of identified patients by an</td>
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<tr>
<td></td>
<td>advanced-skill pain practitioner in conjunction with</td>
</tr>
<tr>
<td></td>
<td>the relevant practitioner</td>
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<td>17.4</td>
<td>Facilitate equity of access to appropriate pain</td>
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<td></td>
<td>medicines and treatments by</td>
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<td></td>
<td>- improving access to pain medicines not currently</td>
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<td>listed on the PBS for which patients are paying</td>
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<td>substantial out-of-pocket costs, through</td>
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<td>- facilitating collaboration between consumer</td>
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<td>organisations, clinician groups, policymakers</td>
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<td>and pharmaceutical industry organisations to</td>
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<td>identify such medicines</td>
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<td>- facilitating research (especially research to</td>
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<td>establish safety and efficacy in children) and</td>
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<td>encouraging industry to apply for PBS listing if</td>
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<td>appropriate</td>
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<td>- facilitating access to Controlled Drugs for</td>
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<td></td>
<td>legitimate users across state borders</td>
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<td></td>
<td>- identifying and addressing barriers to access to</td>
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<td></td>
<td>pain medicines for aged care residents, palliative</td>
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<td></td>
<td>care patients and other groups with limited access</td>
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</table>
Goal 5: Quality improvement and evaluation

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Strategic actions</th>
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<tbody>
<tr>
<td>17.5</td>
<td>Improve consumer awareness about the safe use of over-the-counter, prescription and complementary medicines for pain by  &lt;br&gt; - improving the availability of consumer information materials (see 5.1)  &lt;br&gt; - encouraging pharmacy organisations to facilitate consumer education in local area (e.g. community pharmacy pain information sessions)</td>
</tr>
<tr>
<td>17.6</td>
<td>Train and support prescribers in appropriate use of pain medicines by  &lt;br&gt; - implementing prescriber education programs to improve skills and confidence in prescribing and screening for drug-seeking patients  &lt;br&gt; - integrate prescribing tools (e.g. dose calculators) into best practice  &lt;br&gt; - ensuring periodic monitoring and medicines review as part of pain management plans, including monitoring of adverse effects and improvement of function  &lt;br&gt; - promoting medicines counselling for pain management  &lt;br&gt; - educating prescribers in the acute pain setting in appropriate monitoring to enable safe titration of pain relief for individual patients  &lt;br&gt; - ensuring adequate computer-based recording of pain in hospitals including interventions and adverse events</td>
</tr>
<tr>
<td>17.7</td>
<td>Educate health professionals across clinical groups to identify patterns of medicine use and pain behaviours that indicate need for consultation with other appropriate health professional, by  &lt;br&gt; - improving availability of education materials for health professionals across clinical groups, including pharmacists and pharmacy assistants  &lt;br&gt; - supporting the development and use of e-Health records to identify problems/interactions  &lt;br&gt; - collaborating where indicated with specialists in addiction medicine</td>
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<tr>
<td>17.8</td>
<td>Facilitate communication between all practitioners and pharmacists about pharmacological management, by developing systems to  &lt;br&gt; - ensure all practitioners are informed which medicines are being used  &lt;br&gt; - ensure reporting of adverse drug reactions and interactions back to the prescribing practitioner as well as centrally (ADRAC system)</td>
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<tr>
<td>Goal 5: Quality improvement and evaluation</td>
<td>Strategic actions</td>
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<tr>
<td><strong>Objectives</strong></td>
<td><strong>Strategic actions</strong></td>
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<tr>
<td>18 Improve standards in pain management</td>
<td>Establish a National Pain Outcome Initiative along the lines of the Australian Rehabilitation Outcomes Centre (AROC) and the Palliative Care Outcome Centre (PCOC) for ongoing data management and facilitation of quality improvement</td>
</tr>
<tr>
<td>and developing national benchmarking of outcomes</td>
<td><strong>High priority</strong></td>
</tr>
<tr>
<td>19 Ensure equity of access and appropriate use of non-pharmaceutical interventions</td>
<td>Improve practitioners’ awareness of evidence base for non-pharmaceutical interventions and the appropriate role for each type of intervention in pain management</td>
</tr>
<tr>
<td>19.2 Ensure early use of non-pharmaceutical interventions where appropriate</td>
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<tr>
<td>19.3 Identify and address barriers to access to evidence-based interventions for aged care residents, palliative care patients and other groups with limited access</td>
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<tr>
<td>19.4 Establish a register for all implantable devices</td>
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<tr>
<td>20 Improve standards in pain management services and residential aged care facilities by developing ongoing quality improvement systems</td>
<td>Establish a ‘virtual’ Centre of Excellence in pain medicine to provide clinical, research and education leadership for Australia, and to develop and maintain an accreditation and quality improvement framework for pain services in collaboration with consumers</td>
</tr>
<tr>
<td>20.1 Government funding</td>
<td></td>
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<tr>
<td>20.2 Contact with policy-makers</td>
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<tr>
<td>20.3 National advisory body to provide stakeholder input</td>
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<tr>
<td>20.2 Establish standards for assessment of pain in residential aged care, specifically for individuals with dementia or impaired ability to report pain</td>
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<tr>
<td>20.3 Develop tools for measuring individual patient outcomes over time:</td>
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<tr>
<td>20.3.1 Assess whether current tools capture outcomes important to people with pain, carers and other supporters and communities</td>
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<tr>
<td>20.3.2 Develop tools for people who cannot read or understand English</td>
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<tr>
<td>20.3.3 Allow for differences in outcomes at different points in the patient journey</td>
<td></td>
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<tr>
<td>20.4 Implement key performance indicators\textsuperscript{136} for evaluation to align with Commission on Safety and Quality in Health Care framework</td>
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<tr>
<td>20.5 Determine funding according to defined quality criteria</td>
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### Goal 5: Quality improvement and evaluation

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<th>Objectives</th>
<th>Strategic actions</th>
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<tr>
<td>20.6</td>
<td>Designate one person in each practice setting for cancer and palliative care patients who is responsible for pain management</td>
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<tr>
<td>20.7</td>
<td>Implement a formal process to evaluate and improve the quality of cancer pain treatment throughout the disease trajectory and in the variety of settings cancer pain is managed (Palliative Care Outcome Collaboration exists nationally and has developed benchmarks for pain that can be used as indicators for reporting on the quality of pain management in an organisation)(^{137})</td>
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<tr>
<td>20.8</td>
<td>Develop audit and feedback systems for pain assessments, with results to Clinical Governance (as with falls and pressure ulcers)</td>
</tr>
<tr>
<td>20.9</td>
<td>Incorporate pain assessment, reassessment and management principles into accreditation standards for hospitals, hospices, community nursing services and residential aged care facilities</td>
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<tr>
<td>20.10</td>
<td>Strengthen requirements for multidisciplinary pain management within the Aged Care Accreditation System, and funding of multidisciplinary pain management within the Aged Care Funding Instrument (ACFI)</td>
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<tr>
<td>20.11</td>
<td>Define clinical indicators for pain and palliative care</td>
</tr>
<tr>
<td>20.12</td>
<td>Promote the development of organisational mission statements about pain(^{138})</td>
</tr>
<tr>
<td>21</td>
<td>Develop equivalent quality improvement and evaluation programs specifically for chronic pain management in children and adolescents</td>
</tr>
<tr>
<td>21.1</td>
<td>See above</td>
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Goal 6: Research

A research agenda for pain will be developed to identify and address the gaps in knowledge and practice.

Research into the clinical, social and economic aspects of pain will be supported by appropriate funding.

Translation and dissemination strategies will ensure implementation of research results into practice and policy.

Research findings will be communicated to consumers, with particular attention to health literacy issues.

<table>
<thead>
<tr>
<th>Goal 6: Research Objectives</th>
<th>Strategic actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>22 Enable pain research at a national level</td>
<td>22.1 Designate pain as a discrete field in NHMRC/ARC funding streams and project grant applications</td>
</tr>
<tr>
<td></td>
<td>22.2 Designate basic and clinical pain research as a priority area of research for NHMRC</td>
</tr>
<tr>
<td></td>
<td>22.3 Provide infrastructure and new funding for research at a basic level and at all levels of the health care hierarchy and at all levels of evidence: including self-management and carer support, primary health care, hospitals, pain clinics, universities and government, and quality assurance through to meta-analysis</td>
</tr>
<tr>
<td></td>
<td>22.4 Establish data linkage methodologies between Medicare, PBS and other relevant databases to assist evaluation of treatments and models of service delivery</td>
</tr>
<tr>
<td></td>
<td>22.5 Promote policy-relevant research, including health services, health systems and/or cost-effectiveness research</td>
</tr>
<tr>
<td></td>
<td>22.6 Promote collaboration between chronic pain researchers and cancer researchers around cancer survivors and pain</td>
</tr>
<tr>
<td></td>
<td>22.7 Foster research collaborations such as PaCCSC (Palliative Care Clinical Studies Collaborative) and the peak palliative medicine bodies in each state (e.g. Palliative Medicine Committee of Victorian Cooperative Oncology Group)</td>
</tr>
<tr>
<td></td>
<td>22.8 Develop a national paediatric pain research agenda with an appropriate funding stream to support it</td>
</tr>
<tr>
<td>23 Identify information gaps underpinning all objectives in this document</td>
<td>23.1 Assess burden of chronic pain in acute care system through changing coding focus (see 3.2)</td>
</tr>
<tr>
<td></td>
<td>23.2 In collaboration with people with pain, carers and other supporters, define consumer barriers for poor uptake of pain assessment and interventions, and examine ways to increase consumers’ ability to request pain assessment and therapy</td>
</tr>
<tr>
<td>Goal 6: Research</td>
<td>Strategic actions</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td><strong>Objectives</strong></td>
<td></td>
</tr>
<tr>
<td>23.3</td>
<td>Undertake a comprehensive evaluation of community and clinical interventions for chronic pain management, including models of care, medicines, procedures, complementary interventions, and consumer education/self-management programs. Evaluation should include assessment of global functioning (e.g. return to work status, self rated disability, quality of life) and follow-up over longer time periods (12 months plus).</td>
</tr>
<tr>
<td>23.4</td>
<td>Develop a research agenda, including qualitative, quantitative, health services and knowledge transfer research, in public and private settings, to identify gaps in the evidence base and gather the evidence necessary to improve outcomes for pain management.</td>
</tr>
<tr>
<td>23.5</td>
<td>Assess community attitudes towards pain and people with pain.</td>
</tr>
<tr>
<td>23.6</td>
<td>Collect data on chronic pain as a contributing factor to suicide and increased mortality.</td>
</tr>
<tr>
<td>23.7</td>
<td>Assess impact of chronic pain in childhood on future educational achievement, social isolation, transition to adult chronic pain, and difficulties in transition to the workforce.</td>
</tr>
<tr>
<td>23.8</td>
<td>Assess impact of ageing population and workforce on incidence of pain.</td>
</tr>
<tr>
<td>23.9</td>
<td>Investigate cost-effectiveness of strategies that may reduce the future burden of pain (e.g. obesity management to reduce burden of osteoarthritis).</td>
</tr>
<tr>
<td>23.10</td>
<td>Determine the organisational arrangements or care pathways that support best patient outcomes and cost-effectiveness.</td>
</tr>
<tr>
<td>23.11</td>
<td>Investigate which patient resources and psycho-educational strategies (e.g. pain diaries, medication sheets, patient education) improve outcomes for particular patient populations.</td>
</tr>
<tr>
<td>23.12</td>
<td>Evaluate the introduction of evidence-based complementary medicine by accredited practitioners in an inpatient setting.</td>
</tr>
<tr>
<td>24</td>
<td>Ensure research is relevant to populations with special needs.</td>
</tr>
<tr>
<td>24.1</td>
<td>Identify barriers to pain research in special needs groups (e.g. aged, Aboriginal and Torres Strait Islander, CALD, cognitively/ intellectually impaired, infants, children and adolescents).</td>
</tr>
<tr>
<td>24.2</td>
<td>Develop strategies and measurement tools to overcome barriers.</td>
</tr>
<tr>
<td>24.3</td>
<td>Seek evidence of safety and efficacy of pain treatments frequently used in older people, where there is lack of evidence in this population.</td>
</tr>
</tbody>
</table>
| 24.4             | Improve the evidence base for analgesia based on differing needs:  
|                  | - in the chronic non-cancer pain trajectory  
|                  | - in the cancer trajectory  
|                  | - in the palliative care trajectory, from ‘palliative approach’ to ‘end of life’ to ‘terminal care’  
|                  | - cultural and contextual differences. |
Chronic pain, negative affect and disability:
Preliminary data from the 2005 Statistics Norway Health Survey

Christopher Sivert Nielsen

Background

• The two leading causes of disability are:
  – Chronic pain
  – Psychiatric conditions, mainly anxiety and depression (negative affect)

• These conditions are frequently comorbid
Research questions

1) Does comorbid anxiety and depression account for the high disability rate among chronic pain patients?
2) Does comorbid chronic pain account for the high disability rate among patients with anxiety and depression?
3) … Or are the two largely independent causes of disability?

Descriptive statistics

<table>
<thead>
<tr>
<th>Metric</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>1689</td>
</tr>
<tr>
<td>Age</td>
<td>26 - 65 years</td>
</tr>
<tr>
<td>Chronic pain a)</td>
<td>29.5 %</td>
</tr>
<tr>
<td>HSCL &gt; 1.75 b)</td>
<td>8.2 %</td>
</tr>
<tr>
<td>Disability c)</td>
<td>9.5 %</td>
</tr>
</tbody>
</table>

1) Persistent pain > 6 months
2) Hopkins Symptom Check List. 25-item version
3) Registry data. cutoff = disability > 50%
**Effect of pain on negative affect**

<table>
<thead>
<tr>
<th>Dependent: HSCL</th>
<th>RR</th>
<th>P</th>
<th>PAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (female)</td>
<td>1.50 (1.09 to 2.15)</td>
<td>&lt; 0.05</td>
<td>0.22 (0.05 to 0.40)</td>
</tr>
<tr>
<td>Age (pr. 10–yrs)</td>
<td>1.01 (0.87 to 1.17)</td>
<td>n.s.</td>
<td>0.02 (–0.23 to 0.23)</td>
</tr>
<tr>
<td>Education (&lt; 11 yrs)</td>
<td>1.22 (0.70 to 1.96)</td>
<td>n.s.</td>
<td>0.02 (–0.04 to 0.10)</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>2.82 (2.03 to 3.88)</td>
<td>&lt; 0.01</td>
<td>0.36 (0.24 to 0.47)</td>
</tr>
</tbody>
</table>

Finding:

Chronic pain accounts for 36% of the cases of anxiety and depression (HSCL > 1.75).

RR = relative risk; PAP = Population attributable proportion

**Effect negative affect on pain**

<table>
<thead>
<tr>
<th>Dependent: Chronic pain</th>
<th>RR</th>
<th>P</th>
<th>PAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (female)</td>
<td>1.42 (1.21 to 1.66)</td>
<td>&lt; 0.01</td>
<td>0.18 (0.10 to 0.26)</td>
</tr>
<tr>
<td>Age (pr. 10–yrs)</td>
<td>1.10 (1.02 to 1.17)</td>
<td>&lt; 0.01</td>
<td>0.14 (0.02 to 0.23)</td>
</tr>
<tr>
<td>Education (&lt; 11 yrs)</td>
<td>1.53 (1.23 to 1.79)</td>
<td>&lt; 0.01</td>
<td>0.05 (0.02 to 0.08)</td>
</tr>
<tr>
<td>HSCL (&gt; 1.75)</td>
<td>1.82 (1.49 to 2.12)</td>
<td>&lt; 0.01</td>
<td>0.07 (0.04 to 0.10)</td>
</tr>
</tbody>
</table>

Finding:

Anxiety and depression (HSCL > 1.75) account for only 7% of the cases of chronic pain.

RR = relative risk; PAP = Population attributable proportion
# Pain as a predictor of disability

<table>
<thead>
<tr>
<th>Dependent: Disability</th>
<th>RR</th>
<th>P</th>
<th>PAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (female)</td>
<td>1.17</td>
<td>n.s.</td>
<td>0.09 (−0.07 to 0.23)</td>
</tr>
<tr>
<td>Age (pr. 10–yrs)</td>
<td>2.21</td>
<td>&lt; 0.01</td>
<td>0.81 (0.73 to 0.88)</td>
</tr>
<tr>
<td>Education (&lt; 11 yrs)</td>
<td>1.44</td>
<td>&lt; 0.01</td>
<td>0.07 (0.02 to 0.14)</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>4.66</td>
<td>&lt; 0.01</td>
<td>0.56 (0.45 to 0.66)</td>
</tr>
</tbody>
</table>

**Finding:**

*Chronic pain accounts for 56% of the disability cases.*

RR = relative risk; PAP = Population attributable proportion

---

# Negative affect as a predictor of disability

<table>
<thead>
<tr>
<th>Dependent: Disability</th>
<th>RR</th>
<th>P</th>
<th>PAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (female)</td>
<td>1.40</td>
<td>&lt; 0.05</td>
<td>0.17 (0.02 to 0.32)</td>
</tr>
<tr>
<td>Age (pr. 10–yrs)</td>
<td>2.31</td>
<td>&lt; 0.01</td>
<td>0.82 (0.73 to 0.89)</td>
</tr>
<tr>
<td>Education (&lt; 11 yrs)</td>
<td>1.79</td>
<td>&lt; 0.01</td>
<td>0.11 (0.05 to 0.17)</td>
</tr>
<tr>
<td>HSCL (&gt; 1.75)</td>
<td>2.52</td>
<td>&lt; 0.01</td>
<td>0.13 (0.08 to 0.20)</td>
</tr>
</tbody>
</table>

**Finding:**

*Anxiety and depression account for 13% of the disability cases.*

RR = relative risk; PAP = Population attributable proportion
Controlled for each other:

<table>
<thead>
<tr>
<th>Dependent: Disability</th>
<th>RR</th>
<th>P</th>
<th>PAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (female)</td>
<td>1.11</td>
<td>n.s.</td>
<td>0.06 (–0.03 to 0.22)</td>
</tr>
<tr>
<td>Age (pr. 10–yrs)</td>
<td>2.20</td>
<td>&lt; 0.01</td>
<td>0.81 (0.71 to 0.88)</td>
</tr>
<tr>
<td>Education (&lt; 11 yrs)</td>
<td>1.42</td>
<td>&lt; 0.01</td>
<td>0.07 (0.02 to 0.13)</td>
</tr>
<tr>
<td>HSCL (&gt; 1.75)</td>
<td>1.81</td>
<td>&lt; 0.01</td>
<td>0.10 (0.05 to 0.16)</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>4.30</td>
<td>&lt; 0.01</td>
<td>0.54 (0.44 to 0.65)</td>
</tr>
</tbody>
</table>

Finding:

Almost no change in estimates when controlling for each other

RR = relative risk; PAP = Population attributable proportion

Effect of adjustment

![Graph showing the effect of adjustment on RR and PAP for Disability](image)

- **RR – Disability**
  - Unadjusted a)
  - Adjusted b)

- **PAP – Disability**
  - Unadjusted c)
  - Adjusted d)

a) Adjusted for sex + age + educ
b) Adjusted for sex + age + educ + HSCL
c) Adjusted for sex + age + educ
d) Adjusted for sex + age + educ + chronic pain
Conclusions 1

• Chronic pain accounts for a large percentage of cases of anxiety and depression (36%)
• Anxiety and depression account for few cases of chronic pain (7%)
• This difference is due to the difference in prevalence between the two conditions

Conclusions 2

• Chronic pain accounts more than half of the disability cases
• Controlling for anxiety and depression has insignificant effect on this estimate
• Chronic pain and negative affect are largely independent causes of disability
Limitations

• HSCL is not a clinical measure of anxiety and depression
• However: the prevalence of clinical anxiety and depression in the population is lower than this measure would indicate.
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Appendix

Organizational Rules and Classification of Chronic Pain Clinics 10
Introduction

Pain is a physiological mechanism of paramount importance for the physical integrity of individuals. The nociceptive system comprises nervous structures whose main function is to detect harmful or potentially harmful stimuli, so as to set off reflexive and/or cognitive reactions to avoid lesions, or to prevent a lesion from becoming worse and contribute to its healing.

The importance of pain, especially acute pain, as a symptom of a lesion or an organ dysfunction is well evidenced by the fact that it represents the main reason for the general population to seek health care. Pain is also, countless times, one of the most relevant symptoms for establishing a correct medical diagnosis.

However, except for the vital sounding of the alarm, pain does not represent any other physiological advantage for the organism. In fact, in addition to causing suffering and reducing quality of life, pain is also responsible for physiopathological alterations of the immune, endocrine, and nervous systems, which contribute to physical and psychological comorbidities that may lead to the perpetuation of pain.

Moreover, pain and in particular chronic pain can be present even in the absence of an identifiable lesion, or it may persist after the lesion that originated it has been healed. In this context, pain is not a mere symptom but becomes a disease in itself, as acknowledged in a declaration at the European Parliament in 2001 by the European Federation of IASP Chapters (EFIC)².

Therefore, and within the scope of high-quality health care services, pain management must be seen as a priority, and also as a decisive factor in the necessary humanization of health care. In fact, according to a proposal presented by the International Association for the Study of Pain (IASP) during the First Global Day Against Pain³, pain relief should be acknowledged as a fundamental human right.

In addition to the enormous impact it has on individuals, pain often constitutes a burden for the patient’s family and/or caregivers and represents a loss that is difficult to quantify for society as a whole. It is worth noting that the socioeconomic repercussions of pain have been compared by EFIC to those caused by cardiovascular diseases or cancer.

Acknowledging the importance of pain management, a working group dedicated to pain was created in 1999 by the Directorate-General for Health, which worked in strict collaboration with the Portuguese Association for the Study of Pain (the Portuguese Chapter of IASP) to develop a National Program for the Fight Against Pain (NPFAP), approved by Ministry Decree on 26 March 2001. This plan, innovative at the national and international level (in Europe, France is the only other country with a governmental plan to fight pain), describes the organizational models for pain management in hospitals, including several general guidelines for pain management. The Portuguese government was also the first to establish a National Day for the Fight Against Pain in 1999.

The time frame of the NPFAP ended in 2007, and although some positive progress toward achieving its objectives is recognized, it is clear that the NPFAP will not meet all of its goals. It should be noted that after the development and publication of the NPFAP, several changes took place in the organizational structure of hospitals with implications for the achievement of its goals. Among these changes, we highlight the reformulation of the Hospital Charter, aggregating some hospitals into hospital centers, the reclassification of hospitals into four categories (multi-purpose hospitals (type A), medical-surgery hospitals (type B), local hospitals (type C), and specialized hospitals (type E)), the conversion of some hospitals into public limited corporations, and later, into publicly held corporations, and the approval of the rules for the establishment of university hospitals. It was also noted that the criteria defined in the NPFAP for the classification of chronic pain clinics, based on the classification established by IASP, which follows the American model, are not the most appropriate criteria for the current reality, inasmuch as in some aspects the NPFAP criteria are more demanding than those established by IASP. The recent creation of a Competency in Pain Medicine by the Medical Association, as a way of promoting and recognizing the specialization of doctors dedicated to this field of medicine, also emphasized the need to reformulate those criteria.

The National Program for Pain Management emerged from the need to define new objectives and new operational strategies, as a follow-up to the NPFAP and using the experience gained so far. Hence, in order to obtain epidemiologic knowledge on pain and its distribution in the Portuguese population, to reinforce the organizational capacity of health care service providers, and to improve best practice models regarding pain management, this new National Program for Pain Management should be developed through the implementation, at national, regional, and local levels, of new strategies for intervention, professional development, and data collection and analysis.

² Available through www.efic.org/declarationonpain.html
³ For more information see www.iasp-pain.org.
The National Program for Pain Management is incorporated into the National Health Plan 2004–2010, intersecting with and complementing other national programs in the fields of cancer, rheumatic diseases, and palliative care.

The implementation of the National Program for Pain Management presupposes the participation and collaboration of various health care bodies, namely primary health care, hospitals, the Integrated Network for Continuing Care, institutions of higher education, professional associations, and scientific societies, without precluding the inclusion of other public or private institutions from cooperating as needed, during the course of implementation. The Portuguese Association for the Study of Pain constitutes the permanent scientific interlocutor of the Directorate-General for Health in all aspects of the development, implementation, and evaluation of this program.

2. Context

Pain is defined by the International Association for the Study of Pain (IASP) as “an unpleasant multidimensional, sensory and emotional experience associated with actual or potential tissue damage, or described in relation to such a damage”4. This definition implies that pain has the capacity to affect the individual as a whole, and therefore its management must often be approached on multidimensional levels, taking into consideration not only the sensory aspects of pain, but also the psychological, social, and cultural factors associated with the painful condition.

The prevalence of pain in Portugal was studied by the National Health Observatory in 2002, by means of telephone interviews with Portuguese families that were part of the ECOS sample group5. The study concluded that approximately 74% of those interviewed had felt some kind of pain in the two weeks preceding the telephone interview. The study also revealed that low back pain, osteoarticular pain, and headaches were the types of pain most frequently referred to.

The reduced number of the sample group that participated in the study, as well as the difficulty in determining the severity of pain and its clinical relevance, precluded the establishment of the prevalence of pain in Portugal regarding acute postsurgical pain and chronic pain, the two most clinically relevant types of pain.

Several studies carried out in European countries, with greater sophistication than the ones observed in Portugal in the context of acute postsurgical pain, have demonstrated insufficiencies in the management of this type of pain. This fact is hard to understand and accept because this is a type of pain inflicted by a physician in the course of a therapeutic intervention, and therefore its causes are well known. The management of this type of pain essentially depends on the adequate application of procedural protocols in the perioperative period. The same principle applies to other types of pain inflicted by therapeutic processes or complementary diagnostic tests. On the other hand, it has also been established that as well as preventing unnecessary pain, adequate analgesia in the perioperative period contributes to the reduction of morbidity and decreases the period of hospitalization, thus representing an advantage in economic terms as well.

Chronic pain is usually defined as persistent or recurrent pain that lasts for 3 months or longer and/or persists after the lesion that caused it has been healed. In a recent European study6, which did not include Portugal, the average prevalence of chronic pain in Europe was cited at approximately 20%. Given that this study found significant differences between each country (the prevalence of chronic pain in Norway was 30%, while in Spain it was 11%), it is not possible to make a reliable estimate for Portugal. In any case, the increase in average life expectancy and the consequent aging of the population, as well as the increased longevity of patients suffering from diseases accompanied by pain, allow us to project an increase in the prevalence of chronic pain for the future.

The main causes of chronic pain in Portugal are also unknown, but several international studies corroborate in choosing low back pain as the primary cause of pain. Osteoarticular and musculoskeletal conditions, in addition to low back pain, are other causes of high prevalence of chronic pain, as well as headaches, and on a lesser scale, neuropathic pain. Pain deriving from oncological conditions, often seen as one of the main causes of chronic pain, only represents a small percentage of the chronic pain suffered by patients. However, it has a special importance because cancer is the second largest cause of death in Portugal, and moderate to severe pain is present in 90% of patients with terminal cancer.

---

4 H. Merskey and N. Bogduk, 1994
5 S. Rabiais et al., 2004
Similarly, the socioeconomic impact of pain has not been studied in Portugal. However, a study conducted in the United Kingdom\(^7\) estimated that health care expenses relating to low back pain, which is, as previously stated, the most prevalent chronic pain condition, amounted to €2.5 billion in 1998 alone. However, when the consequent indirect costs are added, namely loss of productivity, absenteeism, and early retirement pensions, the total cost reaches almost €20 billion.

With the exception of specific cases, such as acute postsurgical pain, or pain resulting from labor, pain management should be initiated by, and in most cases restricted to, primary care services. These services must necessarily be the foundation for any strategy that aims to enhance pain management for the general population, especially considering that pain constitutes one of the main motivations for family doctor consultations. In addition to the appropriate technical know-how, the family doctor should have the necessary qualifications to evaluate the social and cultural components of the patient’s environment that may be relevant to the management of pain.

However, the complexity of diagnosis, the need to perform complementary examinations or different therapeutic techniques, and the difficulty of pain management are factors that may lead to the necessity of referring the patient to specialized health facilities that have health professionals competent in pain diagnosis and management.

It is within this context that pain clinics appear within hospitals. They hold distinct levels of specialization according to the respective team and hospital structure in which they are based. The most specialized pain clinics should be at the higher level of the referral system, based on the increasing complexity of the clinical situation or therapeutic strategy.

According to a survey carried out by the Monitoring Committee of NPFAP in 2003, 53 hospitals within the National Health Service had incorporated entities dedicated specifically to chronic pain. This number represents an increase of 40% compared to a similar survey carried out in 1999, before the implementation of NPFAP. However, and similarly to the situation in 1999, the majority of the facilities did not have the recommended levels of differentiation and specialization, particularly as they were monodisciplinary units, lacking psychiatrists or clinical psychologists and doctors with other specialties, with reduced weekly activities and no clinical investigations. It should be noted that the data obtained may be overrated because no independent evaluation was performed.

The same survey stated that only 22 postsurgical acute pain clinics existed, which represents a decrease of 4 clinics in relation to 1999. The reasons for this decrease are hard to understand because such clinics are merely operational units that promote organized action plans and protocols for postsurgical analgesia, which should include all health professionals involved in the perioperative period, namely anesthesiologists, surgeons, and nurses.

Regarding analgesia during labor, it was noted that there was organized activity in 31 of the 53 hospitals that participated in the survey. The maternity centers of Júlio Diniz (Oporto), Bissaya Barreto (Coimbra), and Alfredo da Costa (Lisbon) have obstetric analgesia 24 hours a day, seven days a week. There are more than 15 hospitals offering 24-hour obstetric analgesia and 9 offering it 12 hours a day. Of these hospitals, 16 offer obstetric analgesia 7 days a week. It was also observed that pain intensity was recorded in only 24% of hospitals offering obstetric analgesia.

The Directorate-General for Health published a regulation on June 14, 2003 (no. 09/DGCG), which declares pain to be the Fifth Vital Sign. As such, it has since become considered good clinical practice and mandatory to evaluate and record the intensity of pain regularly, in all health care services, as has long been done for the four “classic” vital signs (respiratory frequency, heart rate, blood pressure, and body temperature). This regulation also indicates the scales that may be used in evaluating the intensity of pain, providing basic instructions for their use. However, it has been observed that this regulation has not yet been implemented in many health care services, perhaps due to a lack of knowledge and awareness of the duties of health care professionals and the public’s right to pain management. The standardization of the evaluation and recording of the intensity of pain could have a significant impact on the treatment of pain in health care units, providing a huge qualitative leap in the humanization of the care provided.

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6 Breivik et al., 2006
7 N. Maniadakis e A. Gray, 2000
3. Guiding Principles
The National Program for Pain Management is based on the following guiding principles:

3.1. Subjectivity of Pain – As it is currently understood, pain does not constitute any biologically measurable indicator, and as such, pain intensity must necessarily be considered to be the way it is described by each patient. Particular attention should be given to individuals who have difficulty in communicating, or who find it impossible to communicate verbally.

3.2. Pain as the Fifth Vital Sign – Pain represents a vital alarm signal for the integrity of the individual and is fundamental for the diagnosis and monitoring of a number of diseases, but it should not be the cause of unnecessary suffering. As referenced in the aforementioned regulation distributed by the Directorate-General for Health, regular evaluation and recording of the intensity of pain constitutes a measure of good clinical practice and should be carried out in all health care institutions.

3.3. The Right to Pain Management – All individuals have the right to adequate pain management, whatever the cause of the pain, so as to avoid unnecessary suffering and reduce the morbidities associated with pain.

3.4. Duty to Manage Pain – All health professionals should adopt pain prevention and pain management strategies for individuals under their care, contributing to their well-being and decreased morbidity, as well as to the humanization of health care. Particular attention should be given to the prevention and management of pain caused by diagnostic methods or therapy.

3.5. Special Treatment for Pain – Pain management should be provided at all levels of the health care network, generally starting with primary health care, and, whenever necessary, continuing through to further levels of specialization.

4. General Objectives
The National Program for Pain Management encompasses three main objectives:

4.1. Reducing the prevalence of non-managed pain in the Portuguese population;
4.2. Improving the quality of life of patients living with pain;
4.3. Rationalizing resources and controlling the costs necessary for the management of pain.

5. Specific Objectives
To achieve the above-referenced general objectives, it will be necessary to achieve the following specific objectives:

5.1. Identify the prevalence of chronic pain among the Portuguese population;
5.2. Identify the prevalence of acute postsurgical pain among the Portuguese population.
5.3. Identify the prevalence of deliveries carried out without recourse to epidural analgesia;
5.4. Improve the current knowledge of health care professionals regarding the diagnosis and management of pain;
5.5. Establish a network of specialized hospital structures for the diagnosis and management of all types of pain;
5.6. Reduce the prevalence of non-managed chronic pain;
5.7. Reduce the prevalence of non-managed acute postsurgical pain;
5.8. Increase analgesia offered during labor;
5.9. Improve access to and rationalize the prescription and use of analgesic drugs.

6. Target Population
The target population of this program must include the entire Portuguese population. Particular attention should be given to patients attending health care centers.

7. Time Line
This program has an extended period of 10 years and will receive a strategic interim evaluation at the end of 2010. This evaluation may result in the need to introduce corrective measures.

8. Intervention Strategies
The following intervention strategies aim to reinforce the organizational capacity and the development of good practice models for pain management approach:

8.1. Reinforcement of the information referring to Regulation No. 09/DGCG of 14 June 2003, issued by the Directorate-General for Health, establishing pain as the Fifth Vital Sign;
8.2. Revision of the organizational regulations regarding chronic pain clinics as stated in the above-referenced National Program for the Fight Against Pain (see Appendix);
8.3. Revision of the organizational regulations regarding acute postsurgical pain clinics, as stated in the above-referenced National Program for the Fight against Pain;
8.4. Revision of the organizational regulations for obstetric analgesia, as stated in the above-referenced National Program for the Fight against Pain;
8.5. Establishment or development of special hospital structures for the specialized treatment of pain;
8.6. Evaluation of specialized hospital structures for the specific treatment of pain;
8.7. Establishment and distribution to health professionals of a hospital referral circuit for patients with chronic pain;
8.8. Establishment and distribution of technical guidelines for health care professionals regarding the referral of patients with chronic pain;
8.9. Establishment and distribution of technical guidelines for health care professionals on how to deal with pain in children;
8.10. Establishment and distribution of technical guidelines for health care professionals on how to deal with pain in the elderly;
8.11. Establishment and distribution of technical guidelines for health care professionals on how to deal with pain in those who suffer from substance abuse;
8.12. Establishment and distribution of technical guidelines for health care professionals regarding the use of opioids in the treatment of noncancer pain;
8.13. Preparation of a list of Homogenous Groups for Diagnosis (GDH) for activities undertaken in pain clinics;
8.14. Preparation of a proposal for a technical regulation regarding opioid therapy and driving;
8.15. Revision of the prescription rules for opioids, specifically referring to medicines subject to special medical prescriptions;
8.16. Preparation of a proposal for the revision of the reimbursement system for opioids.

9. Professional Training Strategies
The following strategies are aimed at health care professionals, and within the scope of communication, to the general population:

9.1. To raise awareness in medical colleges of the need for improvement in dealing with pain in pre- and postgraduate training;
9.2. To raise awareness in nursing colleges of the need to improve pre- and postgraduate training in dealing with pain;
9.3. To raise awareness in psychology colleges of the need to improve pre- and postgraduate training in dealing with pain;
9.4. Preparing a proposal for mandatory professional training in dealing with pain as part of the medical residency program and general and family medicine competence;
9.5. Preparing a proposal for mandatory Professional training in dealing with pain as part of the complementary residency programs in surgery, vascular surgery, endocrinology, physical and rehabilitative medicine, internal medicine, neurology, obstetrics and gynecology, oncology, rheumatology, orthopedics, trauma, and psychiatry;
9.6. Preparing a proposal for the creation of a special cycle of studies dedicated to pain;
9.7. Development of multidisciplinary partnerships for the creation of teaching instruments for basic training on pain;
9.8. Development of multidisciplinary partnerships for clinical training sessions regarding pain, with special emphasis on family doctors;
9.9. Development of multidisciplinary partnerships for training sessions on pain for nurses;
9.10. Development of multidisciplinary partnerships for distributing information to the general population regarding pain, especially on the National Day for the Fight Against Pain.

10. Gathering and Analyzing Information Strategies
The following strategies for gathering and analyzing information focus on the epidemiological understanding of pain and its distribution amongst the Portuguese population, as well as measuring the health benefits arising from pain treatment:

10.1. Development of multidisciplinary partnerships to carry out an epidemiological study on the prevalence of chronic pain and its personal, social, and economic impact;
10.2. Development of multidisciplinary partnerships to carry out an epidemiological study on the prevalence of acute postsurgical pain;
10.3. Quantitative and qualitative assessment of implementing, at the National Health System level, Regulation no. 09/DGCC of 14 June 2003 of the Directorate-General for Health, which promotes pain as the Fifth Vital Sign;
10.4. Performance of an evaluation survey of existing hospital structures dedicated to the treatment of chronic pain;
10.5. Performance of an evaluation survey of existing hospital structures dedicated to the treatment of chronic pain;
10.6. Performance of an evaluation survey on the conditions for administering analgesia in labor;
10.7. Evaluation of the health benefits obtained by the implementation of the program.
### 11. Gantt Chart

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### 12. Follow-up and Evaluation

The Directorate-General for Health is responsible for coordinating, monitoring, and evaluating the National Program for Pain Management, carried out by a National Committee for the Management of Pain, to be officially appointed by the Minister of Health.

In order to collect data and perform a systematic analysis regarding the information on pain, to be provided to the above-mentioned Committee, there will be an effort to promote the creation of a Center for Observation of Pain, in accordance to the informative memorandum no. 46/DSPCS, of 13 October 2006, by the Directorate-General for Health.
The National Program for the Fight Against Pain is evaluated by means of the following indicators:

12.1 Evaluation of Impact

1. Prevalence of moderate or severe chronic pain;
2. Prevalence of moderate or severe acute postsurgical pain;
3. Percentage of deliveries carried out with epidural analgesia;
4. Number of first consultations in chronic pain clinics per million inhabitants;
5. Consumption of opioid drugs per capita.

12.2 Implementation Monitoring

1. Number of chronic pain clinics, of various types, per million inhabitants;
2. Number of acute postsurgical pain clinics, per million inhabitants;
3. Number of doctors with competency in pain medicine, per million inhabitants;
4. “Prevalence” of regular assessment and recording of pain intensity in national health centers (pain as the Fifth Vital Sign);
5. Average delay for scheduling a first consultation in a chronic pain clinics.

13. References


Appendix

Organizational Rules and Classification of Chronic Pain Clinics

1. Chronic Pain Consultation

This refers to all organized forms of diagnosis and treatment of chronic pain that do not necessarily have the characteristics of pain clinics. In this sense, chronic pain consultations may operate with a limited number of doctors (in the extreme, only one), without other health care professionals specifically assigned to pain consultations, or having specific facilities. However, regular activities (at least once a week) should be undertaken, and patients should be registered. The doctor(s) incorporated into the chronic pain consultation clinics should have adequate training for pain management, and there should be at least one doctor with competency in pain medicine, attributed by the Medical Association. A protocol for collaboration should be established with a pain clinic, for referral of patients.

2. Therapeutic Pain Clinic

This is a specific clinic for diagnosis and treatment of chronic pain that carries out some treatments and, whenever necessary, refers patients to complementary services, when possible, through a protocol established with other hospital services. The clinic should have at least two doctors with competency in pain treatment and a psychiatrist or clinical psychologist. Alternatively, a protocol for regular collaboration with these doctors may be established. One of the doctors, with competency in pain medicine, should be the coordinator of this clinic. The assisting team should also comprise at least one nurse. It should operate in specific facilities, even if the facilities are shared, it should have regular activity (at least three times a week), and all patients should be registered. The clinic should be incorporated into an outpatient hospital, when there is one, but it is to be managed through a separate cost center.

3. Multidisciplinary Pain Clinic

This unit focuses on the diagnosis and treatment of chronic pain and comprises a multidisciplinary team. It should include at least one doctor with competency in pain management who coordinates the clinic and its doctors, who must encompass at least three different competencies, including psychiatry, or alternatively two competencies and one clinical psychologist. The team should also have a nurse, a physiotherapist, a social service technician, and an administrative technician. The clinic should be integrated into an outpatient hospital when there is one, should be managed through a separate cost center, operate in its own facilities, and have daily activities, including telephone answering services. It should be equipped to treat patients on an outpatient basis, on an inpatient basis (in collaboration with other hospital services), or in emergency situations. The activities undertaken in the clinic should be subject to therapeutic protocol, be subject to regular evaluations, and may also establish additional protocols for collaboration with complementary medical
specialties. The clinic may be involved in the treatment of acute pain by working with an acute postsurgical pain clinic. Additionally, it should take part in clinical investigation projects and postgraduate training for health care professionals.

4. Multidisciplinary Pain Center
This has the same characteristics as a multidisciplinary pain clinic but should have at least two doctors with competency in pain medicine and should be integrated into a university hospital or university teaching hospital, in accordance to Decree Law no. 206/2004 of August 19. In addition, a multidisciplinary pain center should conduct clinical or basic investigation through independently funded investigation programs, the results of which should be regularly published. It should also promote regular postgraduate training to health care professionals and when solicited, take part in pre-graduate teaching.

Notes on the classification of pain clinics
I. The above-referenced requisites should be understood as minimum requirements. For example, it is stated that any pain clinic may develop or participate in clinical investigation programs, irrespective of the unit’s level of specialization. Similarly, the teams comprising pain clinics may employ more specialized professionals than those mentioned here, and may comprise different specialists, such as an occupational therapist.

II. Given that the criteria for attributing competencies in pain medicine by the Medical Association are very recent, during an interim period, pain clinics will be allowed to operate without a doctor with competency in pain medicine, but all clinic coordinators are advised to obtain this specialization.

III. The organization and degree of specialization for the specific treatment of pain should be adjusted to the hospital into which they are integrated, and should possess at least the following characteristics:
(i) Pain consultation in local hospitals (type C)
(ii) Pain treatment clinics in surgical hospitals (type B)
(iii) Multidisciplinary pain clinics in multipurpose hospitals (type A)
(iv) Multidisciplinary pain centers in university hospitals
(v) Multidisciplinary pain clinics in specialized oncology hospitals (unit E)

The current document was drafted by the Directorate-General for Health, within the scope of action of the Monitoring Committee for the National Program for the Fight Against Pain.

Scientific Coordination:
José M. Castro Lopes

Executive Coordination:
Alexandre Diniz
Designed for People with Chronic Conditions

Service Development and Commissioning Directives

Chronic Non-Malignant Pain

June 2008
Designed for People with Chronic Conditions

Service Development and Commissioning Directives

Chronic Non-Malignant Pain

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I am pleased to introduce the Service Development and Commissioning Directives for Chronic Non-Malignant Pain. This is part of a series of publications which will help remodel services to improve the management of chronic conditions and the quality of life of people living with those conditions.

This publication is issued at an important time. Health and social care services in Wales are facing growing pressures and the prevalence of chronic conditions is continuing to grow. The reviews of Sir Derek Wanless and Sir Jeremy Beecham have told us that new ways of working are needed to deliver health and social care services which are fit for purpose in Wales. Remodelling the way in which chronic conditions are managed is imperative in our drive towards more sustainable world class health and is a process which we must strengthen.

Improving services for chronic non-malignant pain is part of this process. These conditions can affect anyone at any age and from any social background, and can have a dramatic effect on people’s lives. This impacts upon the wider social and economic aspects of life, restricts many life opportunities while also placing significant pressures on health, social care and other services across Wales.

This document aims to ensure that the right services are provided at the right time, by the right person and in the right place. This requires refocusing services and improving the use of resources to meet local needs. Clear care pathways, supported by timely assessment and accurate diagnosis, will become the bedrock of service provision for these conditions, ensuring that both patients and professionals understand their responsibilities at all times. The integrated delivery of high quality services by multi-disciplinary and multi-agency teams should also become a standard feature for managing chronic non-malignant pain across primary, community, secondary and social care settings.

Planners and providers of services should use this document to plan and deliver necessary improvements in the management of chronic non-malignant pain. The approach must be based upon service integration and strong partnership working at local, regional and national levels. The results must be evident in the delivery of flexible, dynamic and dependable health and social care services that clearly meet patients’ needs.

Mrs Edwina Hart AM MBE
Minister for Health and Social Services
Executive Summary

Chronic Non-Malignant Pain (CNMP) covers a wide range of painful conditions affecting individuals physically, psychologically and socially. These common conditions can result in disability and can affect anyone at any age and from any social background. They also have a significant impact on quality of life and the ability of individuals to undertake the activities of daily living. Managing these conditions calls for the input of a range of professionals as well as the support of the voluntary sector and other relevant services.

The growing need for services supporting individuals with CNMP is placing increasing demands on our health and social care system. Secondary care services particularly, experience a great deal of pressure and yet there are clear indications that most forms of CNMP can be managed in primary and community care settings, while ensuring appropriate access to specialists for more complex cases. The Welsh Assembly Government is committed to ensuring evidence-based service provision, underpinned by national and professional standards, to address the needs of the 21st Century. Reshaping services for the management of CNMP is a key building block in this process.

The Service Development and Commissioning Directives for CNMP outline a vision for services in Wales to improve health and well being, minimise the risks associated with living with CNMP, ensure access to the right services, while also supporting and empowering people to maximise their independence in all areas of life. This will require the delivery of well integrated services where care is proactively planned and coordinated between statutory and non-statutory providers of services and where the health, social and broader issues of independence are effectively addressed for all patients.

This vision will be delivered by promoting healthy lifestyles, ensuring prevention and early interventions, and adhering to evidence based practice as well as national and professional guidelines and standards. Improving the management of CNMP will also be planned around care pathways to promote effective pain management within local communities as far as possible. Supporting the independence of individuals will be achieved by calling on the skills and expertise of statutory and voluntary sector organisations.

The Service Development and Commissioning Directives promote the key elements needed to effectively manage CNMP:

- Holistic (biopsychosocial) assessment
- Flexible and responsive services
- Proactive planning
- Evidence based interventions
- Care pathways
- Multi-professional teams
- Individual pain control plans
• Mechanisms to empower the individual to self manage their condition where possible
• Regular monitoring and reviews of the individual’s condition.

Key issues, case studies and other solutions for improving the management of CNMP are highlighted throughout this document to help inform planning decisions.
A number of key actions are also identified at the end of each chapter to ensure a more equitable and consistent approach to service provision across Wales.

These Service Development and Commissioning Directives are aligned to the overarching principles and actions for improving the management of chronic conditions as outlined in 'Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework for Action'. The document is aimed at planners of health and social care services, providers of statutory, voluntary and independent services and individuals living with CNMP as well as their families and other carers. A whole system approach is required to strengthen planning, management and partnership working across traditional organisational and professional boundaries to ensure that care can be provided in the most appropriate and effective way. Delivering this vision for services requires concerted action by a wide range of organisations and demands the commitment of key local decision makers in joint planning and the use of joint resources.
Chapter 1: Setting the Scene

1.1 Introduction

“Chronic pain turns a life into a mere existence. The effects are devastating and often demeaning. It has a negative impact on relationships, inside and outside the home. It involves the loss of independence, dignity and control”

(CNMP focus group, Pontypool)

1.1.1 Health care services are currently unsustainable with an over-reliance on historical, and often inappropriate, models of care. Action is needed to ensure all resources in the community are used to best effect to prevent admission to hospital, to support better care and self-care within the community. Improvements to community services are necessary to ensure high quality services can be provided that are supported by a workforce for sustainable, primary and community-based models of care.¹

1.1.2 Currently there is wide variation in the organisation and delivery of CNMP services across Wales. Some LHBs offer no formal CNMP services, others offer services that only secondary care providers can refer to and the remainder invite GP referrals. Clinics range from small teams providing interventional treatments only such as nerve blocks, to others that offer a large range of options from pharmacology to psychological interventions. This diversity is not a result of patient need and is not patient centred. These Directives aim to redress this variability and to ensure services are more consistent and patient centred.

1.1.3 The CNMP Service Development and Commissioning Directives aim to:

- Improve health and well being and minimise the risks associated with living with CNMP, while supporting and empowering people to maximise their independence in all areas of life

- Integrate and more effectively plan, manage and where appropriate, reconfigure existing pain services and support, to improve service delivery to patients over the next three years

- Simplify access to services and improve communication between patients and professionals ensuring that patients receive the right treatment, by the right person, in the right place and at the right time

- Reduce levels of morbidity and pain related disability

- Redress the balance of service provision across primary, community, social and secondary care

- Provide comprehensive, consistent, preventative and anticipatory care

- Build on the strengths within primary and community based care to integrate services across organisational boundaries
• Help clarify the actions needed to implement these directives and improve service delivery

1.1.4 This document is aimed at commissioners of health and social care services, providers of statutory, voluntary and independent services and individuals living with CNMP, their families and other formal and informal carers. Its purpose is to improve the health, well-being and the quality of life for people living with CNMP in Wales. It is firmly underpinned by the social model of disability, the need for broad ranging medical and psychosocial assessment, and the support of multiprofessional teams working along clear care pathways (see Fig. 1). This is consistent with the Model and Framework for Chronic Conditions Management which will deliver more proactive and planned approaches to managing chronic conditions across Wales.

Fig 1. Four tiers of the Chronic Conditions Management Model
1.5 This document is primarily aimed at adults living with CNMP. It acknowledges that the principles for the effective management of these conditions can be applied to all age groups, including children and young people. These principles, together with the National Service Framework for Children, Young People and Maternity Services in Wales and the work of the Children and Young People’s Specialised Services Project addressing pain, should be applied in developing appropriate paediatric services for CNMP.

1.6 These Directives embrace the principles of equality of opportunity (Sections 77 of the Government of Wales Act 2006) and aim to improve service provision across health and social care. This document aims to identify the need for improved professional and patient accountability and responsibility.

1.7 This document has been compiled in partnership with the Welsh Pain Society and its members. The Welsh Pain Advisory Group, a representative body of the Welsh Pain Society, was also established to help steer this work and will continue to provide advice to planners on evidence based and best practice to support the delivery of effective care for CNMP across Wales. This document has built on previous work undertaken to develop services for patients with pain in Wales led by Professor Michael Harmer. Its overarching aim is to put the needs of people experiencing CNMP at the centre of services. It draws on the advice and views of patients and those who are engaged with supporting the patient including health care professionals, informal carers, the voluntary sector and social care professionals.

1.2 Why is this document needed?

1.2.1 The document is needed to improve pain services for patients across Wales, informing decisions made locally about service provision. Some of the changes outlined within this document have drawn on the work of Dr C Price and her colleagues in Southampton who run a fully integrated, multiprofessional chronic pain service in primary care. The Southampton service has improved patient care, reduced waiting times and has reduced drug spending within the Trust. It also has been cost effective with the average cost savings per patient averaging £204 (Table 1).

<table>
<thead>
<tr>
<th>Health Care Resource</th>
<th>Before PMP (£)</th>
<th>After PMP (£)</th>
<th>Savings (£)</th>
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<td>307</td>
<td>197</td>
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<tr>
<td>Physiotherapy Units</td>
<td>124</td>
<td>45</td>
<td>78 (63%)</td>
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<tr>
<td>Medication</td>
<td>153</td>
<td>137</td>
<td>17 (10%)</td>
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Table 1: The cost effectiveness of a pain management programme (PNP)
1.2.2 CNMP covers a wide variety of painful conditions which can lead to disability, not only because of physical symptoms but also psychosocial factors that accompany physical pain.\(^3\) It can be defined as pain that persists after the point that complete healing should have occurred (3 to 6 months), can be continuous or intermittent and can also be experienced by those who do not have evidence of tissue damage.\(^4\) It can lead to disability due to a range of interacting physical, psychological and social factors.

**CNMP can affect anyone at any age and from any social background but the incidence of chronic musculoskeletal non-malignant pain tends to be linked with socioeconomic deprivation.**\(^5\)

1.2.3 Some people with CNMP can cope with little support from health care services. Others are less able to do so and in this situation pain needs to be effectively managed by taking account of the biological (medical), psychological and social factors that impact upon the individual’s life. This is referred to as the biopsychosocial approach which looks into and beyond medical factors.\(^6\)

1.2.4 Those people who are less able to adapt their lives to cope with the pain experience may have accompanying quality of life issues including depression, anxiety, fear avoidance and social withdrawal.\(^8\) The burden of chronic pain not only affects the individual and his or her family, but also has wider ramifications affecting society,\(^9,10\) for instance:

- **Physical burden** - Pain can lead patients to seek rest because they fear that their pain is made worse on movement. This may result in reduction in physical fitness levels, the loss of muscle mass, and muscle and joint stiffness (de-conditioning). This increases physical disability as individuals associate hurt with harm. This can lead to heart disease, obesity and diabetes.

- **Psychological burden** - People may experience anxiety, depression, anger and fear due to feelings of vulnerability and lack of control when trying to cope with pain. Fear avoidance, fearing the worst (catastrophising) and excessive concern over physical signs (hypervigilance) can increase the pain, decrease pain tolerance and lead to increased use of medication, lower levels of functioning, poorer exercise tolerance, and increased disability. Self-esteem, self-efficacy and self-image may also suffer as a result of the pain experience.

One in four people with CNMP report losing a job due to their pain, one in five say that sometimes their pain is so bad they want to die and a quarter of UK chronic pain sufferers have been diagnosed with depression as a result of their pain.\(^7\)
• **Social burden** - People living with CNMP may become socially isolated as they find it difficult to interact with others, enjoy previous hobbies or work due to the debilitating nature of their pain.

• **Economic and occupational burden**  
  - The overall economic impact of CNMP is considerable given the cost associated with health care provision, wage replacement, compensation and lost productivity. The economic effects for an individual living with CNMP can vary from little or of no importance to the catastrophic.\textsuperscript{11}

  \begin{center}
  **If even 10% of the population had pain every day there would be over 2 billion days of pain in the UK. That is 30–40 days of pain for every one of us.**\textsuperscript{12}
  \end{center}

  \begin{center}
  **In 2002, nearly 4.2 % of the working population was on incapacity benefit, 24% of which was due to diseases of the musculoskeletal system and connective tissue and almost two thirds of which were male; this equated to a cost of £6.7 billion.**\textsuperscript{13}
  \end{center}

1.3 **Categories of CNMP**

1.3.1 The key categories of CNMP are:

  • **Musculoskeletal** - osteoarthritis, rheumatoid arthritis, fibromyalgia, other arthopathies, osteoporotic collapse, low back pain, post surgery, post-traumatic and neck pain

  • **Medically unexplained pain syndromes** - including Chronic Fatigue Syndrome, Myalgic Encephalomyelitis\textsuperscript{14}, chest, abdominal, and pelvic pain

  • **Face and head** - migraine, headache, trigeminal neuralgia, atypical facial pain and dental pain

  • **Neuropathic** - diabetic neuropathy, post herpetic neuralgia, multiple sclerosis, post stroke pain, repetitive strain injury, chronic regional pain syndrome, traumatic injuries and phantom pain

  • **Vascular** - claudication, ischaemic rest pain, Raynauds and angina

  • **Postoperative** - amputation including mastectomy; post surgery thoracic, abdominal and spinal; failed back and neck syndromes.\textsuperscript{15}

1.4 **The Strategic Context for Services in Wales**

1.4.1 *The Review of Health and Social Services in Wales* by Sir Derek Wanless\textsuperscript{16} and Sir Jeremy Beecham’s *Review of Local Service Delivery*\textsuperscript{17} have highlighted that new ways of working are needed to deliver health and social care services that are fit for purpose in Wales. The agenda to improve health services has been set in Wales, led by *Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century*.\textsuperscript{18}
1.4.2 The improvements needed to address CNMP are extensive and complex. *The Model and Framework for Chronic Conditions* sets out a new vision for CCM services in Wales, outlining what needs to change to improve services for Chronic Conditions Management. The *Chronic Conditions Management (CCM) Service Improvement Plan - 2008-2011* identifies the actions needed to implement the *CCM Model and Framework*, improving prevention and the care of those living with chronic conditions as well as supporting people’s independence in all areas of life.

1.4.3 The Welsh Assembly Government is committed to achieving high standards across the public service as set out in *Making the Connections*²⁹. This emphasises the need to design and operate services around the needs of the users, not the provider, taking into account all associated risks, and ensuring high quality, easily accessible and responsive services. Strategic level partnerships, working across all key agencies, are needed to agree common goals, avoid duplication and support the sustainable development of effective and responsive services. Local Service Boards and future service planning arrangements will play an increasingly important role in this context.

1.4.4 CNMP is a key issue for all areas of Wales. Implementation of service change will be based on the assessment of local needs and existing patterns of service provision that must be consistent with the strategic direction outlined in this document. Plans to implement the key actions in these commissioning directives will need to be considered by Local Health Boards and their local partners and should be taken into account in local *Health, Social Care and Well-Being strategies*²⁰, providing a co-ordinated response to all policy objectives and requirements relating to health and social care services in the local area.

1.4.5 This document links closely and is consistent with the overarching aims of *Fulfilled Lives, Supported Communities*, the *Service Development and Commissioning Directives for Arthritis and Chronic Musculoskeletal Conditions*²¹ and the *Therapy Strategy for Wales*²².

1.5 Key Principles and Aims

1.5.1 These Directives focus on the needs of people living with CNMP and aim to ensure that:

- Acute painful episodes are effectively managed to reduce the incidence of CNMP with services adept to addressing psychosocial and physical predictors of chronicity (chronic disability due to pain) at an early stage of pain onset and where recovery is prolonged

- People with CNMP are partners in their management and the aim should be to optimise self-management and self-efficacy promoting independence in all areas of life
- Early assessment and diagnosis of CNMP occurs in order to minimise the burden of pain
- All people experiencing CNMP receive appropriate management that, where possible, is evidence based.

1.5.2 The vision will be delivered through:
- The promotion of healthy lifestyles and relevant support
- Prevention and early intervention as fundamental elements of care across all levels of care to reduce or prevent chronic pain related disability
- Services planned around care pathways to support the provision of effective pain management within local communities as far as possible
- Seamless care provided by integrated multiprofessional teams working across primary, secondary and social care to ensure effective pain assessment, management and evaluation
- Adherence to evidence based practice, national and professional guidelines and standards
- Community-based health care, social care and social support provided in a planned and integrated way by appropriate organisations
- Monitoring performance over time against clear actions and outcomes.

1.5.3 The foundation of these directives is a strategic pathway which underpins the patient journey where access to services, information and self care cuts across each component (Figure 2).

Fig 2. Strategic Pathway of Care
1.5.4 The pathway of care applies to those people with a variety of needs including those who:

a. Are generally well and able to live fairly independent lives
b. Have more significant care needs
c. Have chronic conditions
d. Need emergency treatment or rapid access to social care
e. Need elective care
f. Require social care.

Each chapter of this document addresses the key stages of the strategic pathway providing specific examples and case studies to illustrate the approach and the actions necessary to drive improvements forward.

1.6 Planning and Commissioning Effective Services

1.6.1 Robust planning and commissioning will need to ensure that services are evidence-based, patient-centred, accessible, cost effective and responsive to the needs of people living in pain. A continual cycle of review and improvement will strengthen service delivery. Long term and sustainable services will be developed using local intelligence acquired as an integral part of the planning and commissioning process. This will inform the development of local services and the Health, Social Care and Well-Being Strategies in partnership with service users, their carers and all key stakeholders.

1.6.2 Where evidence is weak or conflicting, robust evaluation of clinical outcomes is essential. Consideration should also be given to what clinical outcomes are relevant and important. Evaluation and audit should be supported by information technology wherever possible, for example the use of READ codes in primary care to accurately record diagnosis.

1.6.3 Local service users are essential in helping to determine how services can best meet their needs. Public and patient involvement will need to be further developed to ensure this is addressed effectively as part of local planning arrangements.
<table>
<thead>
<tr>
<th>Key Elements of Service Planning and Commissioning</th>
<th>Issues for CNMP</th>
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</table>
| Assessment of service users’ needs               | Review the epidemiology of pain  
Audit of current service provision in primary, secondary, tertiary and social care |
| Preventative action and services                 | Prevention across primary, secondary and tertiary care |
| Public and patient engagement                    | Signposts guidance[^23]  
Expert Patient Programme |
| National Standards and Good Practice             | Healthcare Quality Improvement Plan[^24]  
National Institute for Clinical Excellence and Health Care (NICE)  
British Pain Society  
Welsh Pain Society  
International Association for the Study of Pain  
Scottish Intercollegiate Guidelines Network  
Oxford Pain Site, Bandolier |
| Development of care pathways                     | Integrated care pathways[^25]  
Map of Medicine[^26]  
Year of Care[^27] |
| Links with related service commissioning, provision and support | Transition from child to adult  
GP Clusters  
Integrated commissioning arrangements between LHBs, NHS Trusts, Local Authority Services, Health Commission Wales  
Support of National Public Health Services and Regional service arrangements |
| Demonstration of the development of services within all four tiers of the Chronic Conditions Model | Health improvement and primary care prevention  
Primary care and community based services  
Network based, more specialised services  
Complex case managed services |
| Population stratification                        | Risk stratification tools such as the Predictive Risk Stratification Model (PRISM)[^28] |
| Workforce implications and planning              | Designed for Work[^29]  
Agenda for Change[^30]  
Welsh Deanery  
Timescales for delivery and service change |
| Monitoring and evaluation of services            | Local Action Plans  
Annual Operating Frameworks  
Balanced Scorecard |
Chapter 2: Prevention - Reducing the Risks

Aim
To prevent or reduce, where possible, the development of CNMP and related disability through appropriate and early management.

2.1 Background

2.1.1 Effective pain management is of the utmost importance to prevent suffering and reduce or avoid resulting CNMP. The majority of acute pain is managed in primary care and is composed mainly of musculoskeletal pain. The Service Development and Commissioning Directives for Arthritis and Chronic Musculoskeletal Conditions should be consulted for further information.

2.1.2 Other acute painful conditions are also managed in primary care for instance, pain of cardiac origin and neurological origin where the aim is to ensure patients are assessed, diagnosed (where possible), managed and/or referred for specialist services as appropriate.

2.1.3 The overarching aim is to ensure prompt access to appropriate services and the right professional to initiate appropriate management regimens. This may include the primary care team, the community pharmacist and/or registered complementary therapists where there is strong evidence for the use of complementary therapies. Where evidence of good effect exists, the use of complementary therapies should be considered as part of the health care package for patients in pain.

2.2 Healthy Lifestyles

2.2.1 A healthy, active lifestyle is important in preventing certain painful conditions and also in helping establish and preserve function and reduce disability in people with pain. Maintaining a healthy weight and taking regular exercise can contribute positively to patient outcomes following acute and CNMP.

2.2.2 The Welsh Assembly Government supports the integration of nutrition and physical activity policies and programmes, where appropriate, recognising the fact that the effects of diet and physical activity on health often interact. A number of existing strategies and initiatives recognise the importance of work to improve nutrition and levels of physical activity, particularly among children and young people and it is important that these key messages continue to be built upon.

2.2.3 Many people with CNMP are not aware of the benefits of exercise and often avoid exercise due to the perception that it may cause further harm. Evidence shows that quality of life improvements can be gained by people with CNMP through lifestyle changes including safe exercise and other physical activities. Evidence also suggests that exercise and muscle strengthening can have
an impact on function by reducing pain and stiffness; improving muscle strength and endurance; maintaining cardiovascular fitness; supporting weight reduction and contributing to an improved sense of well-being.\(^{40}\)

**Case Study:**

Active for Life is a physical activity scheme funded by the Big Lottery Fund which aims to reduce the risk of heart disease in the Vale of Glamorgan. The exercise referral scheme is a 12 week programme for people who would like to improve their medical condition and/or general state of health by increasing their activity levels. The scheme involves health professionals referring patients to a team of qualified instructors who operate from four leisure centres in the Vale. These types of programmes exist elsewhere in Wales and with training and education, staff could offer such programmes for patients with CNMP.

### 2.3 Secondary Care Acute Pain Services

#### 2.3.1 Pain can arise from apparently uncomplicated surgery\(^{41}\) and on many occasions no structural reason can be found to explain this. Pharmacological, psychological and behavioural methods can be used to effectively manage pain. While these services are traditionally based in secondary care, with the advent of more day case surgery and complex acute pain management issues in primary care, acute pain services need to provide support to primary care teams where appropriate.

**In one study, the incidence of post surgical CNMP was 30-80% in amputation surgery, more than 50% following thoracotomy, 11-57% for scar pain and 13-24% for phantom pain following breast surgery, 3-56% following cholecystectomy and 0-27% for hernia repair.\(^{41}\)**

#### 2.3.2 The advent of acute pain services has improved acute pain management\(^{42} 43 44 45 46\) and one of the ways that services for patients have improved is through standardising care and simplifying acute pain strategies. It has been shown that implementation of various strategies such as education, pain assessment and the use of regular analgesia through the use of an algorithm improves patient outcomes.\(^{47} 48\)

#### 2.3.3 The Acute Pain Management Scientific Evidence\(^{49}\) provides a comprehensive review of evidence-based practice in relation to the management of acute pain. The key, effective elements of acute pain services are\(^{50}\):  

- A collaborative, interdisciplinary approach to pain control including all members of the health care team (acute and chronic pain) and input from the patient and the patient’s family when appropriate.
• An individualised proactive pain control plan developed preoperatively by patients and practitioners (since pain is easier to prevent than to treat)
• Assessment and frequent reassessment of the patient’s pain
• Use of both drug and non-drug therapies to control and/or prevent pain
• A formal institutional approach with clear lines of responsibility

2.3.4 The majority of Trusts within Wales have a formal acute pain service offering support to patients in secondary care and some offer advice to primary and tertiary care centres. This is not consistent across Wales however and further support to all patients would be beneficial.

2.4 Obstacles to Recovery

2.4.1 The transition from acute to chronic pain is not always well defined. It is essential that when professionals assess and triage patients, they understand when to treat and when to refer to other professionals appropriately. There are considerable variations in practice which need to be unified through the design of evidence-based care plans, through education and training and through working in close collaboration with pain experts where appropriate.

2.4.2 A clear example of the transition issues raised in 2.3.1 is when the expected recovery from an acute injury is delayed. For individuals with acute musculoskeletal injury whose progress is slow, it is important to assess them for Red, Yellow, Black and Blue Flags to identify any obstacles to recovery. The biopsychosocial flags are:

• **Red flags** - Signs and symptoms considered indicative of possible serious pathology or of the need for an urgent surgical evaluation
• **Yellow flags** - Psychosocial risk factors that have been shown to be predictive of CNMP associated disability or chronicity e.g. anxiety, depression, catastrophising, fear avoidance, etc. These can predict disability at an early stage, more so than the biological ones
• **Blue flags** - Work features which are generally associated with higher rates of symptoms, ill health and work loss which, in the context of injury, may delay recovery or constitute a major obstacle to it
• **Black flags** - Nationally established policy concerning conditions of employment and sickness policy specific to a particular organisation51.

2.4.3 The flag system can be used as a predictive tool by any healthcare professional involved in managing pain and can be used across a wide range of settings. It should be used early in the
pain experience in patients who appear to have prolonged episodes of acute pain or in patients who appear to have abnormal pain behaviours. They are not labels to be attributed to patients but helpful predictors to help determine the best management approach such as targeted education or anxiety and fear reduction.

2.4.4 Good communication and the availability of relevant, high quality information is essential. This will help individuals identify the need for effective acute pain management, the role of psychosocial factors in disability and recovery, know when to seek professional advice and understand when self management of symptoms is safe and effective. Information on acute and CNMP and its management should be targeted at:

- **The General Public:** Health promotion information and targeted campaigns, such as Welsh Backs, should educate the public and contribute to a better understanding of how to prevent and manage pain. Information should be focused on the whole population (accessible locally) as well as targeted at those at risk of developing CNMP.

- **People at risk of or actually experiencing acute pain:** Good information helps people become informed about their pain and enables them to become active partners in their care. Information is important to help people manage their pain and inform them of further options in care.

- **The Health Professional:** Ongoing information and education is integral to the professional development of all healthcare providers. Health professionals have an important role to play in helping people understand how to manage pain effectively to reduce the impact of long-term pain and the obstacles to recovery as well as helping to minimise the risks of further complications.

**Case Study:**

*The Welsh Backs Initiative is targeting the public, health professionals and employers in promoting the ‘stay active’ message in managing acute, simple mechanical low back pain. The Welsh Backs initiative is responsible for disseminating evidence-based guidelines throughout Wales to ensure people with acute, simple mechanical low back pain receive appropriate help and advice and, if appropriate treatment.*

2.4.5 The general public, and those people living with CNMP, should be encouraged and supported to access appropriate information and learn about pain as part of self-care and self-management. This can be achieved through informal means and via more formal mechanisms including the Expert Patients Programme.
### Sources of Information

The British Pain Society have a website (http://www.britishpainsociety.org) where evidence based guidelines are freely downloadable for both patients and professionals. The Welsh Pain Society website (http://www.welshpainsociety.org.uk/wb/) is under development but will also contain information for patients and professionals. Information can also be obtained from the newly established Chronic Pain Policy Coalition which consists of patients, professionals and parliamentarians who operate at policy level to develop an improved strategy for the prevention, treatment and management of CNMP. Various charitable organisations have useful information that may not be pain specific but address living with a chronic condition.

### Prevention: Reducing the Risks

<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
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<tr>
<td>By September 2009, health planners and commissioners will ensure that patients have access to services in the community that are able to assess, manage and evaluate acute pain and the obstacles to recovery appropriately using best available evidence.</td>
<td>LHBs</td>
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<td>NPHS</td>
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<td>Welsh Pain Society</td>
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<td>NLIAH</td>
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<tr>
<td>By September 2009, evidence-based pathways will be developed and implemented for use across all health care settings to manage acute pain and the obstacles to recovery including valid and reliable assessment and evaluation tools and evidence based care plans.</td>
<td>LHBs</td>
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<td>Welsh Pain Society</td>
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<td>NHS Trusts</td>
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<tr>
<td>By December 2008, standardised patient information on preventative strategies, self management and over the counter medication and treatment options will be easily accessible to the general public.</td>
<td>LHBs</td>
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<td>Community Pharmacies</td>
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<td>Welsh Pain Society</td>
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<td>Social Services</td>
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<td>Voluntary Sector</td>
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<td>Local Authorities</td>
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<td>NHS Trusts</td>
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<tr>
<td>By March 2010, E-learning educational and training packages, aimed at all levels from carers through to specialists in pain management will be available to support better management of acute pain and reduce associated risks.</td>
<td>Educational Establishments</td>
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<td>Welsh Deanery</td>
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<td>Welsh Pain Society</td>
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<td>NLIAH</td>
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<td>Voluntary Sector</td>
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<td>By September 2009, patients with CNMP will be able to identify and access appropriately trained personnel working in local authority exercise referral schemes and other healthy lifestyle programmes currently available for patients with chronic conditions.</td>
<td>LHBs</td>
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<td>Local Authorities</td>
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<td>NPHS</td>
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Chapter 3: Assessment and Diagnosis

Aim
To ensure timely assessment and diagnosis of chronic-non malignant pain to minimise physical, psychosocial and economic impact.

3.1 Background

3.1.1 Making the diagnosis of CNMP will help ensure that patients receive appropriate assessment and management. Professionals able to make this diagnosis and subsequently take the lead in managing these patients effectively, are essential. A diagnosis is also important in ruling out underlying pathology. This can help patients accept that a cure is unlikely and can support and enable effective management of the pain. The disease or condition causing the pain may be incurable, irreversible or may have caused changes which, although the condition no longer exists, has set up a cycle in which pain continues to be experienced.57

3.1.2 Pain is a personal experience, which makes it difficult to define and measure; there are no objective measures to quantify pain. Pain, which is assessed properly, can be remarkably sensitive and consistent, providing data on the pain experience.12 Pain assessment is important in establishing a baseline and to evaluate management approaches.

3.1.3 Many individual conditions exist which have disparate signs and symptoms, treatment or management regimens and outcomes. Individuals may experience nociceptive pain (where normal nerve pathways are followed) or neuropathic pain (where abnormal pathways are followed due to nerve damage). Some people experience a combination of nociceptive and neuropathic pain mechanisms, which can make assessment and management potentially more difficult.

3.2 Holistic Assessment

3.2.1 Pain needs to be assessed using a biopsychosocial approach, use inter-professional and interagency working and needs to be addressed across health and social policy boundaries.58 The biopsychosocial model addresses:

- Biomedical - This can include for instance, ensuring that the pain has been adequately investigated, that previous treatment regimens are assessed for completeness and efficacy, concurrent major medical or surgical problems should be noted and the impact on the pain experience, any major drug and/or substance abuse should also be investigated and any red flags recorded.

- Level of Physical Activity - This can include for instance, level of physical fitness, ability to look after personal care, major co-existing musculoskeletal problems, ability to work and perform activities of daily living.
• Psychological and Social Features -
  This can include for instance, any co-existing major psychiatric or psychological problems, unresolved grief and previous physical or sexual abuse, major misconceptions, difficulty accepting chronic nature of the condition, willingness to change, as well as the yellow, black and blue flags.

3.3 Early Recognition and Appropriate Referral

3.3.1 The development and use of evidence based care pathways with accompanying education and training, means that the majority of patients with CNMP can be successfully managed in primary care. Referral to pain specialist services is only necessary when regular evaluation fails to show an improvement, as may be seen in the more complicated or difficult cases.

3.3.2 The holistic assessment of the needs of people with CNMP should be supported by the Unified Assessment Process. Guidance issued by the Welsh Assembly Government in 2002 has provided steps for the development and implementation of this process. This will enable the effective assessment and management of individual care needs to ensure people can, as far as possible, maintain an independent life.60

3.4 Multiprofessional Teams

3.4.1 Early assessment and appropriate diagnosis is facilitated by a multiprofessional team of health and social care professionals which cover services across the care pathway in all care settings. A well organised multiprofessional chronic conditions team will ensure that services meet the holistic needs of individuals across each of the four levels of the Chronic Conditions Management Model and Framework and are provided as near to patients’ homes as possible. Recommendations on the development of multiprofessional teams are provided in Chapter 4: Management.

Case Study:
The development and re-organisation of the Conwy and Denbighshire Pain Management Service to incorporate multiprofessional team assessment following a biopsychosocial approach has led to positive outcomes. These include highly positive patient satisfaction with the new service, improved efficiency and access to the service and treatment options, changes in management strategies, which include providing appropriate assessment together with the right treatment, to the right patient at the right time.
### Assessment and Diagnosis

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<tr>
<th>Key Actions</th>
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<tr>
<td>By March 2009, biopsychosocial assessment tools, triage and referral protocols will be designed centrally with flexibility built in for local variation in patient needs.</td>
<td>NLIAH</td>
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<td>Welsh Pain Society</td>
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<td>LHBs</td>
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<tr>
<td>By September 2009, planners and commissioners will ensure that assessment tools, triage and referral protocols, are in place and supported by appropriate training across all health care settings to aid early assessment and diagnosis of CNMP.</td>
<td>LHBs</td>
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<td>NHS Trusts</td>
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<td>Tertiary and Regional Centres</td>
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<td>NLIAH</td>
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<td>Welsh Pain Society</td>
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<td>Welsh Deanery</td>
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<td>By September 2009, robust evaluation mechanisms will be in place identifying areas of good practice (that can be disseminated across Wales) and areas where improvements are needed (that need actions planned).</td>
<td>LHBs</td>
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Chapter 4: Management of CNMP

Aim
To ensure that all individuals with CNMP receive management that is appropriate, timely and where possible evidence-based and locally accessible.

4.1 Background

4.1.1 This chapter focuses on the management of CNMP and highlights the importance of a holistic approach to help people with symptoms of pain cope with the physical, psychosocial and economic dimensions of the pain experience. The overarching aim is to ensure that patients can see the right professional, in the right place, at the right time, and receive appropriate evidence-based treatment and advice on ongoing management across all four levels of the Chronic Conditions Management Model. Management should be patient-centred as evidence indicates that this can have a favourable impact on CNMP.

4.1.2 Individual needs will vary and access to services appropriate to need should be secured and care co-ordinated across all four levels of the Chronic Conditions Management Model. Not all patients will require specialist services but those who have complex pain problems may require more expert management. Consistently delivered chronic pain services with access to specific pain management programmes are needed throughout Wales. When a patient presents to secondary care for pain management intervention or to a pain management programme following a period of living with chronic pain, their beliefs, attitudes and behaviours are usually well entrenched. Lack of attention to evaluating and managing these with education and psychological therapies has been one of the major limitations in care.

4.2 The Organisation of Care

4.2.1 The principles and actions of the Model and Framework for Chronic Conditions Management should underpin the organisation of care for CNMP. This will ensure the delivery of co-ordinated, comprehensive and consistent management for these conditions supported by care pathways as an integral part of mainstream service with appropriate shifts being made to ensure care is delivered effectively and safely in community settings and as close to people’s homes as possible. It is important that care is well co-ordinated, ensuring timely and appropriate access to the right services in the right place. Locality Care Service Co-ordinators will play an increasingly important role in this respect.

4.2.3 Integrating services more effectively is crucial to the future of health and social care in Wales. The Community Services Framework outlines some key approaches which can help to ensure that services are effective and meet all value for money challenges:
• The local development of primary care networks or clusters can ensure that specialist, diagnostic and therapeutic services are available locally.

• Specifically tailored arrangements for service co-ordination, such as local networks for patients with CNMP, can promote more effective service collaboration around the user. Improved joint planning and utilising the provisions of the Health Act Flexibilities can improve co-ordination and allow secondary care specialists, primary care clinicians and social services to work as a single team within a defined area.

• Opportunities to use shared service locations such as a Resource Centre or an existing or redeveloped Community Hospital site should also be explored by commissioners as a way of bringing together a number of services.

4.2.4 Establishing Care Pathways for CNMP is an essential part of improving the local management and co-ordination of care for individuals living with these chronic conditions. The Welsh Pain Society, supported by the Welsh Advisory Board will develop centralised care pathways building on the work driven by the National Leadership and Innovation Agency for Healthcare (NLIAH). These centralised pathways can be modified to meet local needs. They will also develop a range of patient and health professional information, protocols and guidelines that can be customised to meet local needs.

4.2.5 Older people, disadvantaged groups, those with end-of-life needs, those with cognitive impairment, mental health problems, those confined to home and substances mis-users all may find it more difficult to get access to appropriate services or may require very specialised support. In planning services, these vulnerable groups need to be considered with specialised help made available, for instance, home visits, use of telehealth/telecare, good communications with psychiatric services and strong links with voluntary organisations. The Welsh Assembly Government will continue to support public services in Wales to improve access for people with disabilities as outlined by the Disability Discrimination Act.65

Case Study:
The North Gwent pain team consists of a multi-professional team. Both the Consultant Anaesthetist and the Clinical Specialist Physiotherapist are present at new patient clinics and are both involved in the patient assessment. Treatment plans are formulated which may include physiotherapy, pharmacology, psychology, and a range of complementary services including acupuncture and trans-electrical nerve stimulation. Treatment strategies are carried out by the appropriate discipline and patients are reviewed by
4.3 Integrating Primary and Secondary Care Services

4.3.1 Health care interventions traditionally begin with a primary care team. The majority of people living with CNMP can be appropriately managed within primary care, by informal and formal health professional, specialist and voluntary care support. Some individuals will require more specialist management in more complex cases for example, in-patient programmes and interventional techniques.

4.3.2 Pain services can be organised in a variety of different ways:

- **Pain Treatment Facility** - Describes all forms of pain treatment facilities without regard to personnel involved or types of patients served.

- **Multiprofessional Pain Centre** - An organisation of health care professionals and basic scientists which includes research, teaching and patient care related to acute and chronic pain. Inpatient and outpatient programs can be offered in such a facility, providing multi-professional and integrated healthcare services.

- **Multiprofessional Pain Clinic** - A healthcare delivery facility staffed by clinicians of different specialties and other non-clinical health care providers who specialise in the diagnosis and management of patients with chronic pain. This type of facility differs from a multiprofessional pain centre because it does not include research and teaching activities in its regular programs. A multiprofessional pain clinic may have diagnostic and treatment facilities which are in nature outpatient, inpatient or both.

- **Pain Clinic** - A healthcare delivery facility focussing upon the diagnosis and management of patients with chronic pain. The absence of interdisciplinary assessment and management distinguishes this type of facility from a multiprofessional pain centre or clinic. Pain clinics can carry out research but it is not a required characteristic of this type of facility.

- **Modality-oriented Clinic** - A health care facility which offers a specific type of treatment and does not provide comprehensive assessment or management. Examples include nerve block clinic, transcutaneous nerve stimulation clinic, acupuncture clinic and biofeedback clinic.66

4.3.3 The management of complex pain problems requires intensive specialist input. Referral to specialist care may be required for individuals who:
• Are not responding to appropriate pharmacological regimens

• Have requested a referral, as is the patients’ rights under NHS regulations

• Are experiencing problematic side effects

• Have red flags on assessment (urgent referral)

• Have yellow, black and/or blue flags

• Are expressing suicide ideation

• Require a pain management programme

• Require pain interventions

• Have not experienced the best methods at an early stage and so chronicity is established.

4.3.4 Pain specialists are essential for interventional therapy, pain management programmes, complex pharmacological therapy and dealing with complex psychosocial issues. Pain specialists also have a key role to play in managing patient care when a person is admitted to hospital. Beds should be available for people requiring in-patient pain management programmes or interventions requiring careful post-intervention assessment.

4.3.5 Providing specialist care in the community should be considered as part of shifting care appropriately into community settings. A specialist member of the secondary care team for example could be commissioned to provide specialist pain services in the community and to cluster GPs across LHB areas. An example of a GP with a special interest approach (GPwSI) is being explored in the Swansea area and this could prove a useful pilot. It is envisaged that the GP and secondary care providers will work closely in primary care assessing and managing pain using evidence-based care pathways.

4.3.6 Community outreach pain services could play an important role in education and patient management when based around GP clusters. A GPwSI in pain management could support this model and also manage a case load of patients in pain who do not require secondary care services. The model of practice will depend on the needs identified by people with CNMP and commissioners and planners of services. Recommendations on the competencies required for GPwSI in Pain Management is being taken forward by the Royal College of General Practitioners in consultation with the British Pain Society and Royal College of Anaesthetists and is forthcoming. Progress on this development can be accessed at http://www.rcgp.org.uk. The ‘Pain Management Service Development Programme’ may be useful in planning cost effective primary care pain services.

4.3.7 Primary care can play an increasingly important role in the early identification and management of red and yellow
flags. A primary care clinic for acute back pain provides a good example of this. These clinics could be run by appropriately trained doctors, nurses, physiotherapists, osteopaths and chiropractors, providing assessment, simple advice and treatment according to evidence based guidelines. They could operate on a 6 treatment basis in liaison with the GP who could then seek other treatment avenues, should ongoing treatment be required. This would support the guidelines suggested by Welsh Backs’.

4.3.8 The model of care chosen will depend upon local and regional planning decisions and essentially must ensure that services are in place to assess CNMP and deliver care appropriate to the pain experience. Guidance is available for the composition and role of specialist pain services and these can be obtained through The British Pain Society (Recommended Guidelines for Pain Management Programmes for Adults, A Practical Guide to the Provision of Chronic Pain Services for Adults in Primary Care) and the International Association for the Study of Pain (Guidelines for Desirable Characteristics for Pain Treatment Facilities).

Case Study:
The residential Pain Management Programme in Bronlyys provides an example of an effective interprofessional approach. Psychologists, physiotherapists, occupational therapists, nurses and doctors work together with the programme participants to improve quality of life through reducing disability and improving the approach that individuals with CNMP and Chronic Fatigue Syndrome take to their condition. Participants learn about their condition, develop coping strategies and receive intensive rehabilitation to address condition related disability through a cognitive behavioural programme.

4.4 Care Planning

4.4.1 Treatment and management interventions for CNMP should be underpinned by evidence-based care pathways and protocols. Multi-professional teams should work to agreed goals across care pathways to ensure the delivery of co-ordinated and consistent care services.

Case Study:
As a result of current challenges in the management of neuropathic pain an integrated care pathway has been developed by a multi-professional group of pain specialists for patients initially managed in primary care. The challenges include variations in practice and inappropriate referrals, need to improve patient outcomes, need to lift prioritisation of neuropathic pain in primary care, lack of national standards, inadequate patient monitoring, poor knowledge base and patients remaining on inappropriate treatment for too long. The care pathway is presented as
4.4.2 A number of tools have been developed to help structure care pathways including the concept of the ‘Year of Care’ and the ‘Map of Medicine’. The ‘Year of Care’ is a planned, comprehensive approach to assisting people with long term conditions to self-manage their care, the goal being to maximising wellbeing, quality of life, and the efficient use of healthcare resources. It is used to systematise the design, commissioning and delivery of services to people with long term conditions. The ‘Map of Medicine’ is a web-based visual representation of evidence-based patient care journeys. As healthcare provision becomes much more specialised, the need to plan and then benchmark clinical practice against national standards whilst incorporating local intricacies is key. Opportunities should be explored locally to explore the use of these tools in managing CNMP.

4.5 Adherence to National Guidelines/Evidence Base

4.5.1 The delivery of effective services must be underpinned by national and professional guidance. There are a wide-range of nationally recognised clinical guidelines and research which provide evidence of good practice and recommendations on service delivery for people with CNMP. A good example of this is the Algorithm for neuropathic pain treatment. Consideration should be given to any future NICE guidelines. Audit of these guidelines should be a regular feature of clinical practice as appropriate for clinical practice within Wales.

4.5.2 The British Pain Society have a wide range of guidelines available including recommendations/information for the use of opioids in CNMP and other pharmacological methods, spinal cord stimulators, and pain management programmes. The National Institute for Health and Clinical Excellence (NICE) offer interventional procedure guidance on a number of pain interventions. Similarly, the systematic reviews of pain related topics undertaken by the NHS Health Technology Assessment Programme, and evidence-based care presented by Bandolier, provide ‘the bottom line’ to advise practitioners on treatment options.

4.6 Workforce Planning

4.6.1 The development of new and the enhancement of existing multi-professional teams with shared care arrangements, will allow some complex conditions to be managed effectively through community and outreach arrangements. Guidelines are available on the composition of
specialist multiprofessional teams including those developed by the British Pain Society.

Evidence indicates that managed care which is co-ordinated by a range of disciplines provide positive outcomes for individuals while helping to reduce demands on secondary care service.\textsuperscript{75}

4.6.2 Modernising service delivery will call for innovation in developing new roles, optimising existing roles, the development and expansion of skills and competencies and working across or breaking down traditional organisational and professional boundaries. Planners and commissioners of services will need to work in partnership with the Welsh Assembly Government, NLIAH, the Workforce Development Education and Contracting Unit and the Welsh Deanery to take this forward within the context of Designed to Work: A workforce strategy to deliver Designed for Life.\textsuperscript{76}

4.6.3 Services for people with CNMP in Wales can benefit from clinical specialists, extended scope practitioners, independent prescribers and consultant therapists, as well as a greater variety of skilled administrative and clinical support worker roles. Non-medical health professionals, including case managers, can be trained to take greater responsibility for managing people’s chronic pain within a multiprofessional team and the voluntary sector is an important part of the workforce supporting patients in pain. Extended scope practitioners in primary and secondary care can help to reduce demands on consultant time in clinics and help to reduce waiting times for clinic appointments.

4.6.4 Community pharmacists are important in providing advice to individuals with pain on the safe and effective use of medicines, providing educational materials, and can assist in patients’ self management in recommending appropriate over the counter medication. They can also advise on general health related activities and undertake medicine use reviews.

4.6.5 Many older adults live in residential or nursing homes. Staff caring for these older adults need to be supported in ensuring pain is assessed, effectively managed and regularly evaluated. This will need to be achieved through education and training and good links with pain specialists.

4.7 Education & Professional Development

4.7.1 Formal and informal education and training of all health professionals involved in the diagnosis and management of CNMP is needed. This will support approaches to care that are professionally integrated and multiprofessional in nature and support workforce planning needs. Given the large body of evidence relating to the role of psychosocial factors in the development, maintenance and recovery from CNMP, education programmes should have expert input from professionals
with a sophisticated understanding of these factors.

4.7.2 Evidence-based continuing professional development e-learning programmes can help to improve current practice and the management of patients with CNMP. The different approaches to psychological training that could be undertaken include teaching psychological concepts, enhancing patient centred attitudes, and developing communication skills to facilitate change and promote independence. Including service users in training programmes where possible could help to enhance effectiveness, enabling the development of more collaborative conversations about managing health.

4.7.3 For health professionals with a specialist interest in CNMP, there should be optional opportunities for the completion of formal qualifications where available as part of Continuing Professional Development (CPD).

4.8 Regional Planning and Service Delivery Arrangements

4.8.1 Arrangements to provide services for CNMP can be made at local and regional levels. Each Local Health Board area in Wales is well placed to work with their local partner organisations which include NHS Trusts, Local Authorities, and the voluntary sector, to provide services which help to meet local needs.

4.8.2 In some cases a regional approach may be more appropriate in terms of planning and funding. Specialist services may only cater for small numbers of patients but these tend to be the extremely complex cases. A regional approach would be beneficial to ensure equity of service provision across Wales. Regionally based services could be organised by collaborative arrangements with the full support and involvement of the relevant service providers and health professionals. Local Service Boards will have an important role in this context. The commissioning of services should take into account the NHS Commissioning Guidance published in 2007 (WHC(2007)023).

Case Study:
The University Hospital of Wales offers a regional centre for neurosurgical interventions for pain management. Cases referred to this service are complex and usually originate from tertiary referrals from pain clinics and neurosurgery departments across Wales and England. Patients have typically been in pain for several years with key pharmacological and operative interventions not helping significantly. Practice is cumulative due to the nature of chronic pain and is labour intensive but success rates are high for a number of conditions and have proven to be cost effective.
## Management of CNMP

<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
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<tbody>
<tr>
<td>By December 2008, plans to develop the workforce to support the implementation of these Commissioning Directives will be integrated into local workforce and training plans.</td>
<td>Welsh Assembly Government LHBs</td>
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<td>Welsh Deanery</td>
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<tr>
<td>By March 2009, planners and commissioners will ensure that plans to reconfigure existing secondary care pain specialist services based on assessment of local patient needs are established to ensure patients with complex CNMP are triaged and referred appropriately using evidence-based care pathways.</td>
<td>LHBs</td>
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<td>By July 2009, planners and commissioners will ensure that secondary care pain specialists hold out-reach community based CNMP clinics based around GP clusters and the assessment of local needs.</td>
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<td>Welsh Pain Society</td>
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<td>NPHS</td>
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<tr>
<td>By March 2009, planners and commissioners will ensure effective acute pain services are available in all NHS Trusts and that these services support complex acute pain problems in community settings where clinically safe and appropriate.</td>
<td>LHBs</td>
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<td>NHS Trusts</td>
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<tr>
<td>By October 2009, planners and commissioners will consider existing evidence and the proposed NICE guidelines (due May 2009) on the treatment of chronic non specific back pain and commission appropriate services according to this evidence which may include professionally registered and regulated complementary therapists, including osteopaths and chiropractors.</td>
<td>LHBs</td>
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<td>Professional Regulatory Bodies</td>
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<td>Welsh Pain Society</td>
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<tr>
<td>By April 2009, structured signposting on CNMP management will be developed to address a range of learning needs from carers through to CNMP specialists.</td>
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<td>Welsh Pain Society</td>
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<td>Key Actions</td>
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<td>By December 2009, evidence based care pathways for the</td>
<td>LHBs</td>
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<td>biopsychosocial management of CNMP across care settings will</td>
<td>NLIAH</td>
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<td>be designed centrally with flexibility built in for local variation</td>
<td>Welsh Pain Society</td>
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<td>in patient needs</td>
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<td>By December 2009, planners and commissioners will ensure that</td>
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<td>integrated primary care services for managing people with CNMP</td>
<td>NHS Trusts</td>
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<td>are established across Wales driven by evidence-based care pathways.</td>
<td>Healthcare Inspectorate Wales</td>
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<td>By December 2009, patients with CNMP will have individual care plans</td>
<td>Welsh Assembly Government</td>
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<td>in place, written in partnership between patients and health care</td>
<td>NLIAH</td>
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<td>professionals, and informed by care pathways.</td>
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<td>By March 2009, regular periodic monitoring of medicines for CNMP</td>
<td>Social Services</td>
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<td>will be undertaken and guidance and support given on the</td>
<td>Welsh Pain Society</td>
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<td>prescribing and use of medicines for the management of CNMP.</td>
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<td>By March 2009, planners and commissioners will ensure that</td>
<td>LHBs</td>
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<td>appropriate in-patient and day case facilities are provided for</td>
<td>NHS Trusts</td>
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<td>patients with CNMP</td>
<td>Healthcare Inspectorate Wales</td>
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<tr>
<td>By September 2009, planners and commissioners will develop</td>
<td>Welsh Assembly Government</td>
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<tr>
<td>mechanisms to identify and share good practice for CNMP across all</td>
<td>LHBs</td>
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<td>four levels of the Chronic Conditions Management Model.</td>
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Chapter 5: Facilitating and Managing Independence

Aim
To ensure that people with CNMP become partners in their care to support self-management and maximise their independence.

5.1 Background
5.1.1 A key role for health and social care services, in partnership with voluntary sector organisations and others, is to help people with CNMP to maximise their independence. Approaches should support self-management, building on the resources and knowledge individuals and their carers have. They should also include the support offered by the Expert Patients Programme. Not all patients are ready or able to self-manage and/or assume the role of a partner in their care so strategies need to support attaining these.

Case Study:
The Case Manager in level 4 of the Chronic Conditions Management Model and Framework will be a cornerstone in providing co-ordinated care for individuals with highly complex needs including the management of pain. The Case Manager will be responsible for individual care needs and will be a key one point of contact throughout the care journey for each individual. They will need to have appropriate training and skills in pain management to deliver this care and support.

5.2 Social Model of Disability
5.2.1 The Welsh Assembly Government has adopted the Social Model of Disability as the basis for all its work on disability. The Social Model recognises that disadvantage and social exclusion often stem from the barriers disabled people face rather than from an individual’s impairments. All service commissioners and planners should understand and implement the Model when planning their services. Service planners and commissioners should be aware that people with CNMP often have impairments that may be hidden from view (including fatigue) and that the severity of symptoms of the condition may fluctuate significantly from one day to the next.

5.3 Improving Quality of Life
5.3.1 Although it is unlikely that individuals with CNMP will be cured, much can be done to improve quality of life and maximise independence by ensuring:

- Flexible, accessible and responsive services that are multi-disciplinary and seamless
- Training, information and advice on positive lifestyle options and self-management strategies
- Training, education and support for behavioural and cognitive change
• Accessible employment or appropriate social security support, training and education
• Fully accessible buildings, transport, housing, leisure facilities and pursuits
• Clear roles between all appropriate agencies offering advice and support to enable people to fulfil their potential

5.4 Access to Information/Signposting

5.4.1 People with CNMP can experience a great deal of uncertainty and anxiety regarding their future. A wide range of expertise is needed to support people during this period, being sensitive to their concerns and providing advice, relevant links and information resources. Health care professionals and supporting agencies need to be made aware of such resources to achieve such goals.

5.4.2 Local services such as ‘user led information points’, signposting by health professionals to help-lines, patient support groups and other sources of information can help to support people during assessment and following diagnosis. The Expert Patients Programme can also play an important role in helping people with CNMP by raising levels of confidence and improving self management skills.

5.5 Self Management

5.5.1 Supporting people to self manage helps make the best use of health and social care resources. To be effective, self-management should be woven throughout care pathways and be based upon partnerships between the individual and professionals at all stages of the spectrum of care.

Recent research suggests that self-management can help in reducing some of the symptoms associated with pain but may or may not affect the actual level of pain.  

5.5.2 Accurate information and advice on the safe and effective management of pain is essential to allow self-management to take place, supporting independent living. Advice and guidance should focus on how pain should be managed and when health professional advice should be sought. The accessibility of information in public places including internet, pharmacies, libraries, and social care environments for example, is important to help educate people about managing their pain.

5.5.3 Lay-led self management training including the Expert Patients Programme are playing an increasingly important role in supporting people who are living with chronic conditions. These programmes provide appropriate training to help people
learn new skills to manage their conditions more effectively and confidently.

5.5.4 Self-help groups also provide people with CNMP with the opportunity to discuss their concerns, experiences and day to day symptom management with other people with similar experiences. Such groups can help to reduce isolation for some individuals with CNMP and can be a source of reassurance, support and information. They can also develop their own activities that reinforce positive self-management strategies and lifestyle choices such as exercise.

**Case Study:**
Patient support groups such as the charity Coping and Living in Pain established through the Velindre Pain Management Programme, Cardiff, can contribute to the maintenance of coping behaviours for those who have completed pain management programmes.

5.6 Public and Patient Involvement

5.6.1 Involving service users is crucial to developing services that meet patients’ needs and is a key recommendation of the Review of Health and Social Care in Wales and Sir Jeremy Beecham’s Review of Local Service Delivery. Developing user involvement is also a key principle within Designed for Life and the Public and Patient Involvement Signposts Framework. Health and social care planning should take account of this guidance to ensure that people with CNMP are fully engaged in contributing to service design and implementation of the services they utilise.

5.7 Personal Assistance and Social Care

5.7.1 For people who need personal assistance, services should be responsive and flexible to take into account the fluctuating and unpredictable nature of their pain. It is important for service users to have control over the care and assistance they receive so these can be tailored to fit individual daily needs.

5.7.2 ‘Direct Payments’ by Social Services offer improved quality of life for disabled people. While the Direct Payment option may not be suitable for all service users, it is important that support and guidance are available to enable people with CNMP who may decide to take up this option if they chose to do so.

5.7.3 Some individuals may require certain aids and adaptations made to both their home settings and places of work. Timely assessment and subsequent adaptations can have a major impact on independence for a person with CNMP. Services and information are provided by health and social services as well as voluntary sector organisations such as the Red Cross. Provision of such, needs to be undertaken in a co-ordinated
way. The Welsh Assembly Government has made funds available to NHS trusts and local authorities to facilitate the development of integrated equipment stores to ensure a more responsive, cost effective and consistent provision.

5.7.4 Consideration of home care, day care and personal assistance should be built into joint and unified assessments of needs for people with CNMP.

5.8 Informal Carers

5.8.1 Many people living with pain are supported by informal carers. CNMP can create a profound sense of helplessness, resulting in feelings of frustration which can manifest as irritability, and sometimes anger, directed at members of the family and other carers. Informal carers experience many social disadvantages including loss of income and work opportunities, isolation, stress and fatigue. It is essential that unpaid carers have access to support and information if their contribution to the effective rehabilitation and management of people living with pain is to be maximised. Carers often need choices about whether or not they wish to take on a caring role and if so, be offered appropriate support, information and courses that can help them learn how to cope, manage their own health and well being and keep on caring. A number of voluntary sector organisations provide free information and support to carers. The Expert Patients Programme also offers the ‘Looking After Me’ course which helps carers to manage their own lives whilst being a carer.

5.8.2 Assessments for care services under the Unified Assessment Process include a section on the role of any carer who provides or intends to provide ‘regular and substantial’ care. This should trigger the requirement of the Carers Equal Opportunities Act 2006 that carers should be informed of their right to a separate assessment of their needs.

5.9 Social Inclusion

5.9.1 CNMP has an impact on an individual’s access to a wide range of opportunities including employment, housing, benefits, and pensions. In terms of employment, significant barriers to finding or returning to work exist for people with CNMP. There are a number of factors which make the return to work a risk, including the loss of benefits and crucial social support and care. Limitations in transport, location and physical access to places of work can also reduce the options for individuals seeking employment. Retention in work and back to work programmes are important in securing a future for people with CNMP. Improving liaison with occupational health services is needed to ensure opportunities to refer patients to occupational health specialists are provided, especially for individuals living with CNMP who return to employment.
5.9.2 The Department for Work and Pensions has produced a green paper *A New Deal for Welfare: Empowering People to Work.* This document proposes a new gateway to benefits for people with illness and disabilities and includes the provision of in-work support to ensure people continue working. Recent proposals for welfare reform express the intention to roll out the Pathways to Work initiative across the UK by the end of 2008.

This endorses the condition-management approach piloted in the Pathways areas, supports the biopsychosocial model to ensure that people off work, because of illnesses or disabilities, can be helped in the pathways to recovery and to return to work by providing the right opportunities, support and encouragement; by helping people to understand and manage their health condition; and by using cognitive behavioural therapy principles and related interventions.

### Facilitating and Managing Independence

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<tr>
<th>Key Actions</th>
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<tr>
<td>By December 2009, individual patient care plans will include a category for self management, for access to rehabilitation and the Expert Patients Programme.</td>
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<td>Voluntary Sector</td>
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<td>By March 2009, appropriate information and support on CNMP will be widely available, signposting services provided by health care providers, the voluntary sector and local user-led self-help groups.</td>
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<td>Welsh Pain Society</td>
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<td>Expert Patient Programme</td>
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<td>By March 2009, opportunities for respite for carers of people in pain will be provided in line with existing guidance.</td>
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<td>Social Services</td>
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<td>By March 2009, unpaid carers will be actively involved in joint care planning arrangements to help them look after themselves and the person living with pain.</td>
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<td>Social Services</td>
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<td>Voluntary Sector</td>
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Appendix 1: Acknowledgements

The Welsh Assembly Government would like to thank all key stakeholders that have contributed to the development of these Service Development and Commissioning Directives. Special thanks are extended to Professor Michael Harmer, all members of the Welsh Pain Society, and the Welsh Pain Advisory Board for their positive contribution and commitment to this publication.

Particular acknowledgement is made to the following people who have been instrumental in advising the Welsh Assembly Government and developing the final document:

Mrs Ann Taylor  
Senior lecturer  
Cardiff University

Mrs Shelagh Lloyd  
Clinical Nurse Specialist in Pain Management  
University Hospital of Wales

Dr Owen Hughes  
Consultant Counselling Psychologist/Head of Pain Management Service  
Powys Local Health Board

Mrs Sue Jeffs  
Consultant in Pain Management  
Nevill Hall Hospital

Professor Ceri Phillips  
Health Economist  
Swansea University

Mr Justin Taylor  
Chiropractor  
Vale of Glamorgan  
Welsh Pain Society

Welsh Assembly Government Lead Officials:

Mrs Helen Howson  
Head of Community Health Strategy and Development  
Welsh Assembly Government

Mr Ross Gregory  
Health Strategy Advisor  
Welsh Assembly Government
Appendix 2: References


14 Further information available at: http://www.nice.org.uk/page.aspx?o=111636


Accessible at: www.wales.gov.uk/signposts


26 Further information at: http://www.mapofmedicine.com/
27 Further information at: http://www.dur.ac.uk/ccmd/yoc/

28 Further information available at: http://www.wales.nhs.uk/IHC/page.cfm?pid=27213


32 NICE. (2006). Non-rigid stabilisation procedures for the treatment of low back pain


38 Food and Well Being: Reducing inequalities through a nutrition strategy for Wales (2003), Food Standards Agency Wales, Welsh Assembly Government


55 Further information available at: http://www.wales.nhs.uk/sites3/home.cfm?orgid=537


60 Further information available at: http://www.wales.nhs.uk/ihc/page.cfm?pid=10204


67 COMM-IT (2007). For further information please email: developyourpainservice@napp.co.uk
Further information at: http://www.dur.ac.uk/ccmd/yoc/

Further information at: http://www.mapofmedicine.com/


British Pain Society  http://www.britishpainsociety.org/

National Institute for Clinical Excellence  http://www.nice.org.uk/

Health Technology Assessment Programme  http://www.ncchta.org/

Bandolier http://www.jr2.ox.ac.uk/bandolier/

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